Members'
MAGAZINE
SPRING 2016

nras
National Rheumatoid Arthritis Society

Biosimilars

What they are and what you need to know.

So similar, but different.

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DONATION PAGE

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Spring 2016

Dear Members

By Ailsa Bosworth

Chief Executive

As I write this spring has most definitely sprung and the sun is shining, however with Easter early this year, who knows what the weather may still hold for us – in recent times we've had both snow and a heatwave near Easter! Anyway, the year has got off to an incredibly busy start – who stole the first 3 months? I am looking forward to the long Easter weekend which by the time you read this will have been and gone but at this point in time I am looking forward to a short break with a few days off.

We have a new three year organisational strategy which came into place a the beginning of the year which also includes a new three year fundraising strategy with a goal to increase income by 25% by 2019, so we can reach and help more people. The new strategy can be downloaded from the website, so do take a few moments to have a look at that. We have deliberately set ourselves challenging, but we believe, achievable targets against which we can measured. Your thoughts and feedback are more than welcome.

The Chair of the NRAS Board of Trustees, Graeme Johnston, who has served the society loyally for six years retired at the February board meeting and I'd like to take this opportunity to publicly thank him for all he has done over many years to support the charity. Greame found us originally through participation in one of the RA Self Management courses which he says changed his life, having recently retired early from Price Waterhouse Coopers due to his RA. We all wish him well in the future and are delighted that Graeme will continue to volunteer his services where appropriate.

As a result of the retirement of some trustees in the last twelve to eighteen months we have now taken on four new trustees and the whole team welcomes Zoe Ide, Ellie Andrews, Gordon Taylor and Kirsten Jane Fox.

Zoe and Ellie both have RA themselves; Kirsten and Gordon have close family members with RA. All come from varied backgrounds bringing great expertise and skills to the NRAS Board which will help us to take forward and deliver the three year strategy. We are indebted to Steve Crowther, Treasurer Trustee who takes over as interim Chair.

Two more of our existing long standing Trustees will also be retiring this summer and so further appointments to the Board will take place later in the year.

I would like to draw your attention to the article on biosimilars and the current issue of switching which is on page 15. For Members currently on biologics this will be of particular interest to you.

I am pleased to tell you that I am going to Windsor Castle on 13th April to receive my MBE which is very exciting and gives me a great excuse for a new outfit and possibly a hat! I promise to share photographs in the autumn magazine.

That's all from me for now, very best wishes to you all for an enjoyable and healthy year ahead.

Ailsa

New NRAS Trustees

Ellie Andrews

Gordon Taylor

Kirsten Fox

Zoe Ide

NRAS Staff

Welcome to three new members of staff:

Chris Cordrey as Head of Development, Shivam Arora as Web & Digital Media Officer and Nikki Tee, Fundraising Assistant. We are delighted that they have all settled in well into the NRAS team and you'll find out more about each of them in future magazines.

Members' MAGAZINE

Contents

Meet the Team

Beverley on Val

I have known Val for 2 years and one of the first things that strikes you is her happy nature, fun sense of humour and that wicked laugh! Val works in the Fundraising department and she is absolutely amazing at organising events and getting people where they need to be at the right time with all the relevant information. She is also so dedicated; the number of times she has been stood in the wind and the rain, at weekends cheering people on is beyond count. I myself have witnessed her holding on to the edge of a tent with one hand trying to stop it from flying away in the wind, getting soaked and at the same time trying to sell raffle tickets! She deserves a medal for her endurance! Val is the also our Queen of frothy coffee making in the office!

She is married and has 2 children, loves tennis (don't ever divulge the results if she hasn't had time to watch the match) and like many others of us in the office is a great Strictly Fan.

Val Eyre

NRAS Fundraising
Events Coordinator

Clare on Ailsa

Formidable, driven, a pioneer – no I'm not describing the bionic woman (though going through airport security with Ailsa can be like that with all her joints' bolts and screws). I am of course describing Ailsa our fearless leader.

Many of you will have met her at various events and conferences. Certainly all of you will have read about her, so you know about how she works tirelessly for the cause. However, let me give you a glimpse of the woman behind the professional image…the mother, wife, grandmother, cat lover, soprano and music lover. Married to the debonair Brian, mother to the talented Anna, grandmother to three lovely girls including the most recent the beautiful Alba (just turned 1), to Ailsa, family is all important and snatching those special moments at weekends with them is a real boost. However when the grandchildren are not around the house is not that quiet as cheeky Conti and superior Islay, Ailsa's cats certainly make their presence felt.

When not burning the midnight oil on "NICE submission papers" or "conference presentations" etc. Ailsa finds singing very therapeutic and sings with a local choir. While choral singing and more classical music tends to be her main interest I will let you into her guilty secret…she also likes Take That and has been to see them play live at the O2. Being named in the Queen's New Year Honours list is nothing but deserved and I am delighted to say that she has further been honoured recently when winning the Sue Ryder Woman of Achievement award in the community category as well as the further overall winners' award the Robyn Jones Southern Woman of Achievement Award 2016. Needless to say we are all incredibly proud of the "boss".

Ailsa with her Woman of Achievement awards.

Photo courtesy of Maidenhead Advertiser

> We are all incredibly proud of the 'boss'

Membership

Dates for your Diaries!

NRAS "Rheum For You" Annual Conferences

We are delighted to announce the NRAS Annual Conferences for 2016 however this year, to try and reach even more people, we will be holding three mini conferences instead of just one main one. Plans are afoot to hold these conferences in:

- **Eastwood Park**, Wotton-under-Edge, South Gloucestershire on 11th May
- **Novotel Nottingham Derby** - 29th September
- **Forth Valley College, Stirling** on 4th October This *"Gathering"* is being organised by our wonderful Scottish Ambassadors

As with previous years it will be **free to attend** for all NRAS Members accompanied by one guest.

Additional guests and non-NRAS Members are welcome to attend for small registration fee of £10.00. Alternatively, non NRAS Members can join the society on the special direct debit introductory offer of just £10 for the first year and therefore can attend the event for free. Please contact us using the details below and we will send you the special offer form.

Interesting speakers and interactive sessions are being planned for each event but spaces will be limited so please do contact us to register your interest in attending. You can do this via the website at **www.nras.org.uk/memberevents** or email **membership@nras.org.uk** with your full name, postcode, the Members' event you are interested in attending and also tell us if you will be accompanied by a guest(s). Alternatively call the office on 0845 458 3969 and ask to speak to the Membership team. Further information, including a full agenda, venue details and directions etc., will be sent out nearer the time. We look forward to seeing you all very soon!

NRAS Gift Membership

The perfect gift that keeps on giving

If you're struggling to find the perfect gift for a loved one who lives with RA then why not give the gift that lasts all year? If you have a family member or friend who lives with rheumatoid arthritis, why not consider buying them a year's Membership of NRAS?

For just £25 for the whole year, they will receive all the benefits of NRAS Membership. We'll supply a gift card which has a space for a personal message from you. This can be sent directly to the recipient or we can send it to you so you can give it to them personally.

If you have RA yourself and are being pestered by family and friends to give them some ideas what you'd like as a birthday, anniversary, mother's day or father's day present, why not put them out of their misery and suggest they buy you the gift of your next year's NRAS Membership or if they really want to spoil you Lifetime Membership. NRAS Membership is a thoughtful and unique gift that will not only benefit you but thousands of others like you. The more people who join the society the stronger our lobbying voice and the more we can do across the UK. There are only so many hankies, socks and bath cubes one needs in one's lifetime after all!

Membership of NRAS is the best way to hear the latest RA news and enables us to better support you, your family, your health professionals and others living with this disease.

If you are interested in Gift Membership, please call the Membership team on **01628 823524** or go to our website **www.nras.org.uk/gift-membership** to print off the Gift Membership form and send it back to us by post.

Join the NRAS family today – Your Society here for you every step of the way with RA!

Healthcare Champions Awards 2016

Nominate your Healthcare Champion 2016 and help us share best practice in treating rheumatoid arthritis and juvenile idiopathic arthritis.

Many people across the UK with RA and JIA are receiving excellent care and support in coping with their disease. The dedication and professionalism of the healthcare professionals working in this field play a vital role in getting the best outcomes for patients.

NRAS will be holding its 5th Healthcare Champion Awards in Westminster to celebrate the excellent work that healthcare professionals are doing across the UK and highlight such good practice to an audience including parliamentarians, commissioners, clinicians, health care professionals and key decision makers.

We need your help to find those healthcare professionals who are really championing the cause of RA and JIA patients and who maintain an excellent service and perhaps go above and beyond the call of duty, despite the challenging financial environment, resource pressures and time restraints imposed on them.

The closing date for nominations is **Friday 12th August 2016**. From your nominations, individuals and teams who have demonstrated outstanding work to support rheumatoid and/or juvenile arthritis patients will be shortlisted as finalists. We will then invite the ten top Healthcare Champions in the UK, and those of you who successfully nominate them, to attend a high profile awards ceremony in Westminster in November 2016.

Previous winners of the NRAS Healthcare Champions Awards have told us that they were overwhelmed to be nominated by their patients and it means often far more to them than professional awards do, as it is from the people they serve every day and that to have this acknowledged in such a public way is very rewarding and humbling.

Nomination forms can be requested by emailing membership@nras.org.uk or by calling the team on 0845 458 3969 or you can submit your nomination online via: **www.nras.org.uk/healthcarechampions**

We look forward to receiving your nominations!

Do you know a Healthcare Champion?

Nominate your Healthcare Professional Star today

You can nominate anyone or a team that you believe really deserve that acknowledgement.

- Consultant Rheumatologist
- Paediatric Rheumatologist
- GP or GP Surgery or Practice nurse
- Pharmacist
- Podiatrist
- Occupational therapist
- Paediatric or Rheumatology specialist nurse
- Physiotherapist
- Orthopaedic Surgeon
- Whole rheumatology team
- Whole paediatric team

Living with RA

Preventing Ulnar Drift in your hands

Tips to help you manage

By Sarah Bradley

Clinical Specialist
Occupational Therapist,
Poole Hospital

and

Christina Macleod

Occupational Therapist,
Royal Hampshire County
Hospital

What is Ulnar Drift?

Many people with Rheumatoid Arthritis find the joints in their hands are affected. Especially the joint professionals call the Metacarpophalangeal joint (MCP) shown in green in Figure 1.

When your joints are hot and swollen it causes the soft tissues around the joint to be stretched. In the MCP joint it can cause sideways drifting of the fingers known as Ulnar Drift.

If you notice these changes in your joints it is advisable you practice joint protection techniques and do hand exercises.

Joint protection

When your joints are hot and swollen, it can cause long term problems unless you are careful in your daily tasks. Being careful using your joints when they are swollen is called joint protection. Joint protection techniques to protect the MCP joints include not getting up from a chair pushing on your hands and fingers; If you are opening jars and turning taps, always use the force towards your thumbs and not little fingers. There is a really good booklet published by Arthritis Research UK that goes into more detail about how to protect all your joints. NRAS have copies if you'd like one sent to you call our helpline 0800 2987650 or email enquiries @nras.org.uk. Or your Rheumatology department might have a copy.

Exercising with a splint

An exercise splint can be used to exercise the MCP joint and the muscles that support it. The splint holds the MCP joints straight so you can bend and straighten the Proximal Interphalangeal joints (See Diagram 1 joints marked in blue) and Distal Interphalangeal joints (See diagram 1 joints marked in orange). Patients are encouraged to do 10 repetitions of the exercises three times a day. The exercises should be done in conjunction with good joint protection and taking your medication.

If you have found the information useful and would like advice on how exercise may benefit your hands, ask your Rheumatologist, Rheumatology practitioner or GP for a referral to a Hand Therapist or Rheumatology Occupational Therapist/ Physiotherapist depending on the structure of your local service.

Distal Interphalangeal Joints

Proximal Interphalangeal Joints

Metacarpophalangeal Joints

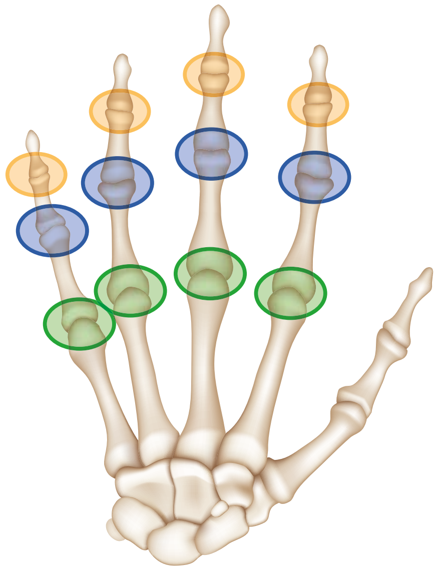
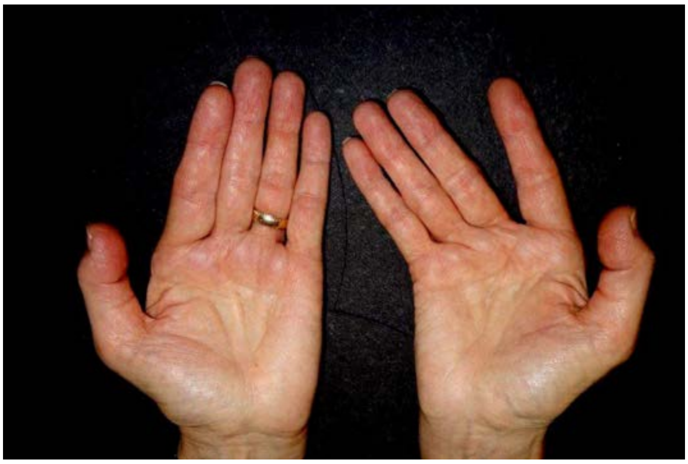
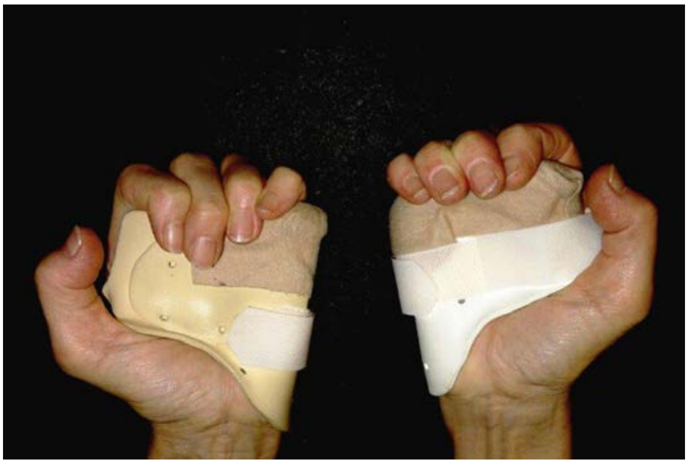


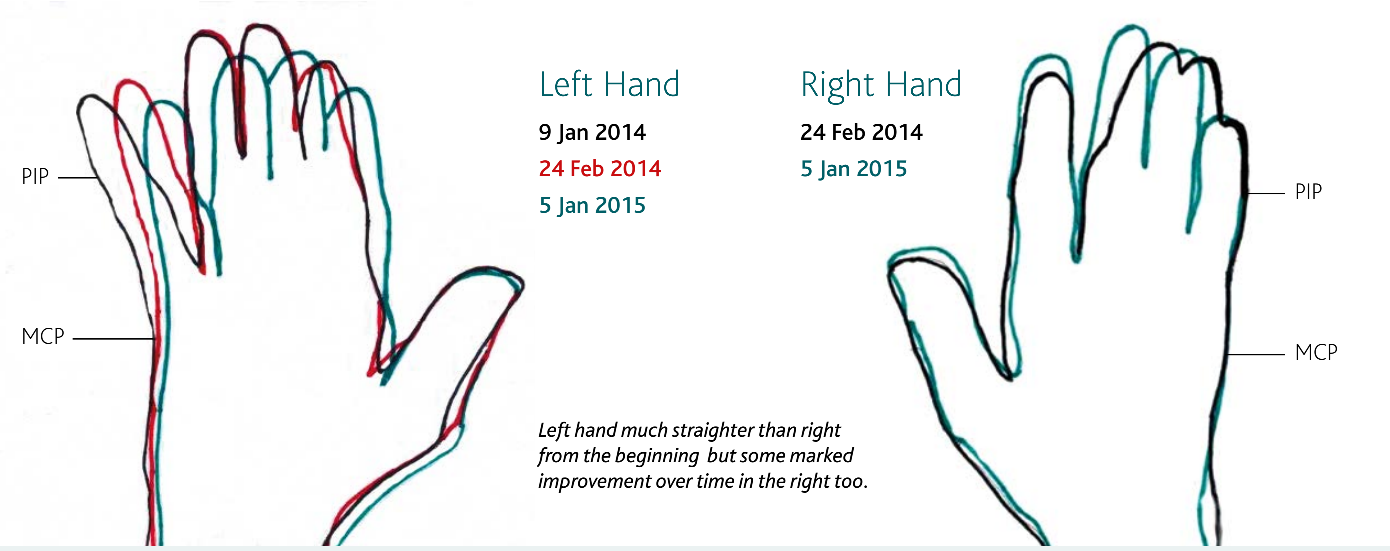
Figure 1: bony anatomy of the fingers

Figure 2: Ulnar drift affecting the fingers





While not the most attractive these exercise splints can make a real difference.



Left hand much straighter than right from the beginning but some marked improvement over time in the right too.

Some patient comments

after following the exercises with the splints.

A patient who got improvement

"I can now make my fingers go together and straight on the table. It has stopped small change [coins] from falling through my fingers. I am so glad - doing the exercises has really made a big improvement – thank you."

(But the patient did the work)

From a patient who was given the splints to prevent further deterioration

"I found that these do help to stop ulnar drift when exercising hands. Together with other hand exercises the tendons were stretched in the hands and fingers. Unfortunately the drift on my hands is too far advanced for the condition to be corrected fully. If the splints had been available at an earlier stage they would, hopefully, have helped to prevent such bad deterioration."

A patient experience of hand exercises

"I have had Rheumatoid arthritis for many years and have always tried to exercise regularly. About two years ago the Occupational Therapist recommended the SARAH hand exercises. I have found them very easy to do. I keep all the equipment – foam cubes, elastic strips, Play-doh etc in a basket beside my chair so that it is all to hand and easy to pick up when I sit down.

Since starting the exercises, my hands have improved. But I was still finding that the Ulnar drift in my hands wasn't improving. So my consultant referred me again to the Occupational Therapist for another hand assessment.

This time she recommended that I have an exercise splint for my hands. She took a diagram of my hands with the palm flat on the page – just like school so we could see if there was any improvement. Then she gave me an exercise splint and told me to do the exercises 3 times a day, but in reality I don't manage this every day!!

Despite my not quite managing to do the exercises every day when I went back for my assessment there was improvement in my ulnar deviation. I can now touch all my fingers to the opposing thumb – that means I can touch the tip of each finger with the tip of the thumb on the same hand. The Left hand has a lot more improvement than the right. My left hand is also straighter than the right. I use my right more and don't always use joint protection.

My Occupational therapist (OT) lives very close to my home and when walking the dog I occasionally would meet my OT and I would attempt to move the dog lead without her noticing onto my forearm so she didn't tell me off for how I was holding the lead!! Guilt would set in – I'm sure I am more aware of joint protection because I walked past my OT's house regularly! A daily reminder! Not something you want but it can be useful."

– Susan Chilcott-Monk

By Dr James Galloway

Kings College London
with trainee Gloria Lliso

Living with RA

Weight, diet and rheumatoid arthritis

As we enter the second half of the second decade of the 21st century, the global community is growing ever more aware of the health challenges associated with weight.

Worldwide there are now over 1 billion adults who fall into the category of 'obese'. UK estimates now suggest that the NHS is spending more on obesity-related disease than it does on smoking-related illnesses. Indeed, the UK has the highest prevalence of obesity of any Western country, with the proportion of obese adults haven risen from just 7% in 1980 to 25% in 2012.

The World Health Organisation defines obesity as abnormal or excessive fat accumulation that results in a risk to health. A crude measure of obesity is the body mass index (BMI), a person's weight (in kilograms) divided by the square of his or her height (in metres). A person with a BMI of 30 or more is generally considered obese (see Figure 1). Obesity itself is not a disease, but nonetheless it has far reaching implications. Obesity is a major risk factor for several illnesses, including diabetes, heart attacks, stroke and cancer.

> NHS is spending more on obesity-related disease than it does on smoking related illnesses.

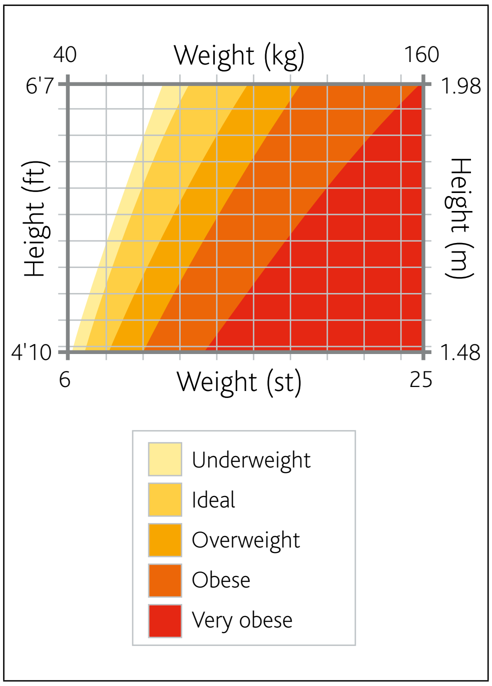


Figure 1. Definitions of obesity

Despite worldwide acceptance of the problem, as a society we are still in the early days of learning how to help people reduce weight in a sustainable manner. Many diets exist, although the results are mixed, and few studies demonstrate long-term success. Current thinking in the medical arena is that there is a 'window of opportunity'; people who are normal or slightly overweight, but not yet obese, likely represent the group most important to target from a public health strategy.

Studies exploring the frequency of obesity in people with rheumatoid arthritis suggest that the patterns are similar to the general population. However, the situation is different for people with rheumatoid arthritis. We know that rheumatoid arthritis directly impacts upon weight. Patients with arthritis lose muscle bulk (termed 'sarcopenia'). As muscle is heavier than fat BMI may underestimate obesity in people with rheumatoid arthritis. What is clear is that people with a BMI above 25 with rheumatoid have worse outcomes, reporting more pain and higher levels of disability.

A further challenge facing people with rheumatoid arthritis is how to tackle weight gain. The management of obesity evolves around two aspects: dietary change and increased exercise. People with rheumatoid arthritis are disadvantaged here, as exercise is impacted upon by the inherent nature of the disease. Whilst in general exercise is beneficial for joints - in particular it helps strengthen the surrounding muscles - it can be painful. During times of disease flare it is important to try and rest particularly inflamed joints but it is equally important to keep moving and exercise a limited amount.

In addition, doctors often prescribe corticosteroid tablets (e.g. prednisolone) as a treatment for rheumatoid arthritis, and a direct side effect of corticosteroids is weight gain.

The positive news however is that studies have shown that by far the most important step in achieving weight loss is dietary change: research shows that compared to diet alone, exercise plus diet only has a small additional benefit on weight loss.

Advice on diet

Many patients, who enquire about diet and arthritis, are specifically interested to know whether a certain diet is beneficial for their symptoms. Unfortunately this is challenging to answer. Whilst there is no doubt whatsoever that many people with rheumatoid notice diet influences their joint pains, everyone seems to be slightly different. Recommending a one-size fits all diet as a panacea for RA is therefore unhelpful. Studies (and there have been many) have failed to convincingly show any one diet has specific benefit for rheumatoid arthritis.

Therefore, the most sensible and pragmatic advice is to adhere to the standard recommendations for a balanced diet that apply to the population at large. Individuals may get to know their own particular foods that they need to avoid, but the overarching principles should be as follows:

Appropriate calorie intake:

Maintaining the correct amount of calories in diet is important in achieving a healthy weight. It can sometimes be difficult to know how many calories we should eat. There are a number of online calorie calculators that can help you understand how many calories there are in different types of food. (www.nhs.uk/Livewell/weight-loss-guide to find the calorie counter and much more.). Understanding calorie content in food must then be combined with knowledge of how many calories you need. The amount of calories you need can be estimated from your weight and your daily activities. Again, several free online calculators exist (www.calculator.net/calorie-calculator).

Balancing the source of calories:

A number of guidelines recommend that the total caloric intake should be broken down by percentage of intake according to food type:

- 45 to 65 % from carbohydrates
- 10 to 35 % from protein
- 20 to 35 % from fat

Carbohydrate – there are many sources of carbohydrate and each varies with regards to effect upon your bodies sugar metabolism (referred to as the glycaemic index of the food). Diets containing foods with a low glycaemic index have been associated with lower risks of developing diabetes, coronary heart disease, and some cancers. Therefore an important way of achieving a healthy diet is to replace carbohydrates having a high glycaemic index (e.g., pizza, rice, pancakes) with a low glycaemic index (e.g., fruits, vegetables). It is also important to try to reduce foods with added sugars (as opposed to natural sugars). Many prepared foods and ready meals contain astonishing amounts of added sugar, as do soft drinks and alcoholic beverages.

Protein – it is healthier to eat a variety of protein-rich foods, including fish, lean meat such as poultry, eggs, beans, peas, soy products, and unsalted nuts and seeds. Studies suggest that it is better to avoid protein sources with trans and saturated fats, including red and processed meats.

Fat – consumption of fat in diet has always been controversial. It appears that the type of fat is as important as the quantity of fat in our diets. So called 'trans' fats contribute to coronary heart disease, while polyunsaturated fats (found in oily fish) are protective. Trans fatty acid consumption should therefore be kept as low as possible. The major sources of trans fats include margarines and partially hydrogenated vegetable fats. These fats are also present in many processed and fast foods.

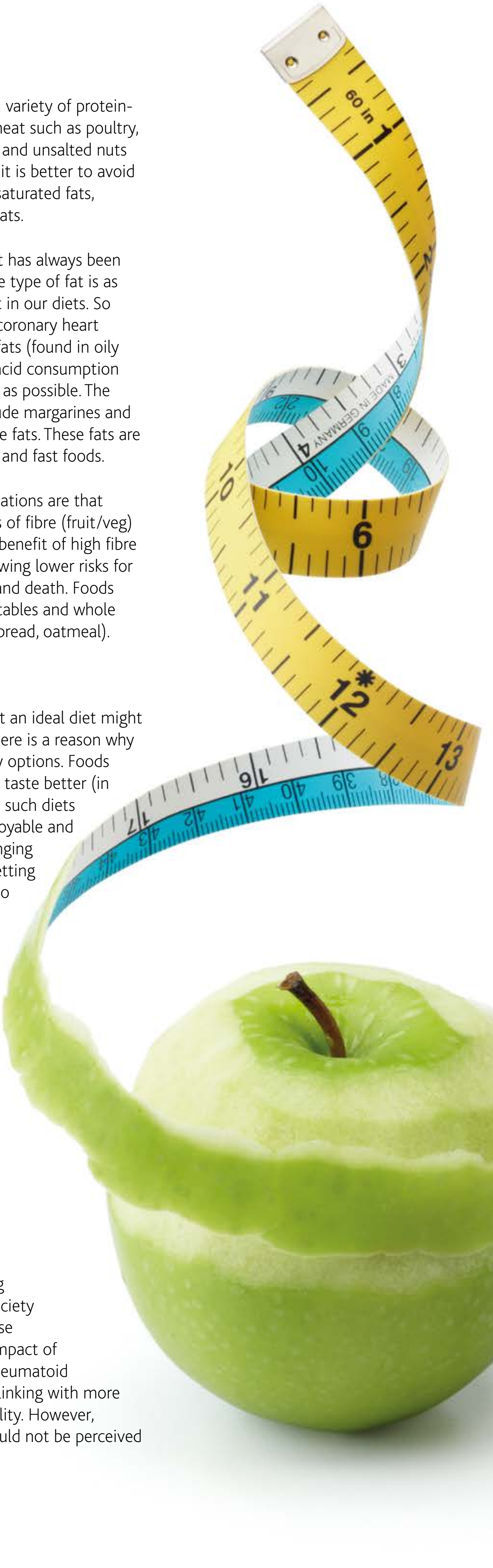
Fibre – the current recommendations are that adults consume at least 5 items of fibre (fruit/veg) every day. The evidence for the benefit of high fibre diets is strong, with studies showing lower risks for heart disease, diabetes, cancer and death. Foods high in fibre include fruits, vegetables and whole grains (brown rice, whole grain bread, oatmeal).

Getting support

It is all very well describing what an ideal diet might include, but we all know that there is a reason why people chose to eat less healthy options. Foods higher in refined sugars and salt taste better (in fact there is good evidence that such diets are addictive). Eating is also enjoyable and has a pivotal role in society, bringing families and friends together. Setting out to change your diet as a solo venture is an enormous task. Thankfully, there are now many weight loss groups available (e.g. weightwatchers, slimming world) that can help. A crucial advantage of dieting as part of a group is the motivational support obtained. Many GPs are now able to refer to weight loss classes, although sometimes having to pay a membership to a group can be a motivation to attend in its own right!

In summary:

There is no doubt that the rising spectre of obesity in western society is going to have dramatic adverse consequences for society. The impact of obesity for people living with rheumatoid arthritis is exaggerated further, linking with more pain and greater levels of disability. However, having rheumatoid arthritis should not be perceived as a barrier to weight loss.



Fundraising

Fundraisers with RA

Fundraisers who don't let RA stand in their way!

1 Rosie Rhodes ran with 4 friends in the York Colour Run in June 2015. As a team they raised £460. Rosie was diagnosed with RA in 2013 just after her 18th Birthday.

2 Emma Kendrick from Northampton was diagnosed with JIA when she was just 13. In 2015 Emma travelled up to North Wales and zip wired her way on Europe's longest zip wire, reaching speed of 100mph. Emma faced her fear and raised a fabulous £311 for NRAS.

3 Katy Evans is no stranger to taking on testing personal challenges. Last year was no exception when she swam the distance of the English Channel over the period of one month in her local fitness pool. When Katy was 27 she was diagnosed with RA, her health took a downturn but 5 years on Katy achieved something she could not have imagined 5 years ago. Swimming every day in November to achieve 33.1km and raising a fantastic £640.

4 Julie Jasper's determination shines through and in October recruited some friends to join her in the 5K Brighton Colour run. Julie was diagnosed in 2013 and has found great help and support from NRAS. This was Julie's second year and was even hoping to run some of the 5K in 2015. Julie was delighted to donate £352 in sponsorship money.

5 Moyra Younie and her friend Jen far exceeded the fundraising target they set when they ran the Loch Ness 10k in September 2015. Moyra has lived with RA now for the past 15 years. The training was as challenging as the event itself but Moyra was undeterred and raised a whopping £658

6 2015 was the second year that Rebecca Studholme ran the Coniston 14 – 14 miles around Lake Coniston. However in 2014 a month after completing the challenge Rebecca was diagnosed with RA. After her diagnosis Rebecca had amazing support from family and friends and was supported on the run by her Dad. Her aim was to help raise awareness about this disease, she also raised donations of £187.

7 Fiona Maddock wanted to give something back to NRAS after being "struck down by RA" (her words) in 2013. She struggled to do quite simple everyday tasks let alone continue to enjoy her sporting activities. Fiona did not give up though and in 2015 found herself signing up and completing her first Ladies Novice Triathlon! She finished 68th out of 180 and raised an amazing £650.

8 Dragon boat racing was Donna's challenge of choice and she joined the Northwick Knights as their drummer and took to the water in the Dragon boat race in June 2015. Donna had a great time and raised a wonderful £130 for NRAS.

9 Steve Valentine has found that even with all the pain and sometimes physical difficulties RA brings him, cycling has been a sport that he can still challenge himself with. Steve does not shy away from setting himself a challenge of a major distance and over the past two years has cycled Coast to Coast and last year completed The Dragon 250mile event. This year Steve has taken up one of the NRAS places in the Ride London event.

All these people's continued support of NRAS is amazing and we wish all these people and other amazing people who throw the gauntlet down in the face of their RA and say…"Go on then, just you try to stop me!" You are all truly inspirational.

nras
National Rheumatoid Arthritis Society

Not everyone is into such physical challenges, with or without RA, (I mean the only thing I like running is a bath!) There are other less energetic ways to support your society; have some friends round for a themed NRAS Tea Party or hold a marathon scrabble tournament; virtual treasure hunts or quiz nights.

For many people living with RA every single day can be a challenge. The reason we share these stories with you is to take off our collective hats to those that can do these amazing things, as what they show us is that a diagnosis of RA doesn't have to mean STOP. It can, for some people, mean on your marks, get set and GO.

Clare Jacklin, NRAS Director of External Affairs

Rebecca Studholme Coniston

Katy Evans – Swim the Channel in a pool


Julie Jasper – Brighton Colour Run

Moyra Younie – Loch Ness Marathon


Donna McLaughlin – Race the Dragon

Rosie Rhodes – York Colour Run

Steve – Training

Fiona Maddock – Triathlon


Emma Kendrick – Zip Wire Challenge

Living with RA

Osteoporosis & RA

What is osteoporosis?

By Tina Stoodley

Osteoporosis Nurse

National Osteoporosis Society

What is osteoporosis? First, a bit of Latin, because there's a clue in the name. The word osteoporosis means porous bones and it occurs when the struts which make up the mesh-like structure within bones become thin. This causes them to become fragile and break easily following what could be just a minor bump or fall. These broken bones are often referred to as fragility fractures.

That's osteoporosis and it's surprisingly common: almost one in two women and one in five men over the age of 50 will break a bone, mainly due to poor bone health. Women are particularly susceptible because they tend to lose bone strength quite quickly for several years following the menopause.

Early identification of those at high risk of a fracture is really important so, if needs be, an appropriate drug treatment can be prescribed to keep bones as strong as possible.

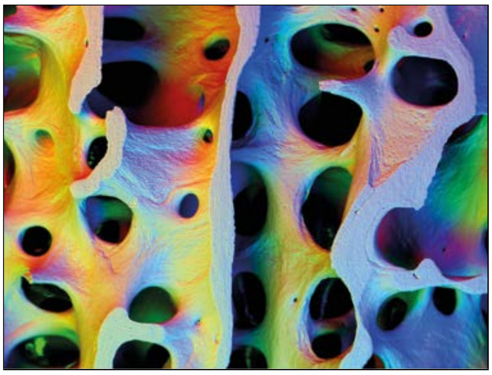


Figure 1. Healthy bone ©Alan Boyde 2015

How do I know if I have osteoporosis?

Osteoporosis does not have any symptoms in itself and frequently the first time anyone knows that they have fragile bones is if a fracture occurs. In younger postmenopausal women, for example, a broken wrist following a fall might be an early sign of fragile bones.

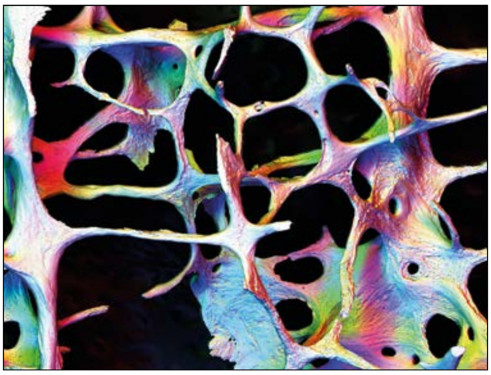


Figure 2. Unhealthy bone ©Alan Boyde 2015

Osteoporosis does not generally stop the healing process from taking place and fractures as a result of osteoporosis will still heal in the same way as they do in people without the condition. However there may be some permanent changes in shape or loss of height in the back if there have been any spinal compression fractures.

Fractures due to osteoporosis in the spine (vertebrae) usually occur in the lower or middle part of the back and are often referred to as spinal or vertebral compression fractures. Here the bones become squashed or compressed because of their reduced strength and they may be described, following an x-ray, as 'crushed', 'collapsed' or 'wedged' depending on how the bone is affected. If a number of wedged fractures occur together then the spine can tip forward causing a forward curve. This is often called a kyphosis or what used to be known as a dowgers hump, another sign of osteoporosis.

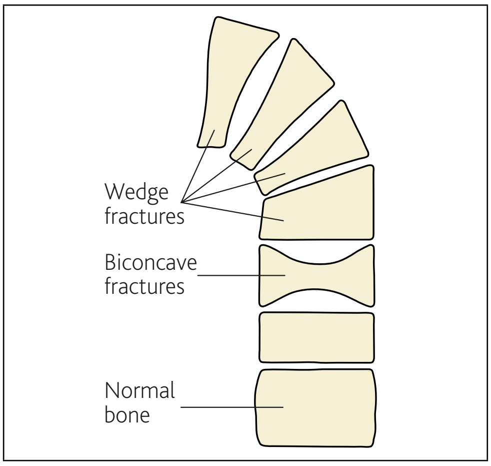


Figure 3. Spine showing compression fractures

Scans and tests

Osteoporosis is diagnosed using a bone density scan, known as a DXA scan (Dual Energy X-ray Absorptiometry). A diagnosis of osteoporosis on a scan can be useful but it is not a perfect measure of bone strength. Scans do not show the quality of bones –whether the structure has broken down inside - which is why the results are used in combination with other risk factors to decide how high the risk of breaking bones currently is. One of the risk factors that is known to increase the risk of osteoporosis and fractures is **rheumatoid arthritis (RA)**.

There are a number of other factors that can increase the risk of osteoporosis and fractures such as age, gender, family history, low body weight, smoking, excessive alcohol consumption and some medical conditions such as Crohn's or coeliac disease. Additionally medications such as glucocorticoid steroids, anti-epileptic medication and some breast and prostate cancer drugs can also increase risk.

How does rheumatoid arthritis increase my risk of developing osteoporosis?

Research has shown that even if someone's bone density isn't particularly low, RA seems to make bones more fragile and increases the risk of fractures.

Although the reasons for this are not fully understood, it is thought that the detrimental effect of RA on bone strength may occur as a direct result of the inflammatory disease process. There is also a well-known link between the use of glucocorticoid steroids and a person's risk of fracture. Although it is a very important medication to reduce the inflammatory process in RA, doctors aim to prescribe the lowest dose of steroids possible for the shortest period of time.

Lack of exercise can be another cause of osteoporosis as RA will restrict many people's ability to exercise easily. Keeping as mobile as possible will not only help with some of the RA symptoms but will also help to reduce the impact of RA on bone strength.

How is osteoporosis managed?

If you are diagnosed with RA you will be regularly followed up by your doctor or rheumatologist. As part of this review, your doctor should consider your risk of osteoporosis and fracture and may also arrange for you to have a bone density scan.

Note from NRAS:

If your annual review has not included a discussion about osteoporosis and fracture risk, be sure to ask your rheumatology team about it next time.

This in combination with other risk factors will help to decide how high your current risk of breaking a bone is and whether you need an osteoporosis drug treatment. A "fracture risk assessment" tool called FRAX has been developed by the World Health Organisation to help health professionals identify who is most at risk of breaking bones in the next ten years. A diagnosis of RA is included in this tool.

If you are considered to be at a high risk of breaking bones easily, the good news is, there is plenty you can do to keep your bones strong.

- Eat a well-balanced calcium rich diet and aim to get 700mgs of calcium a day, the equivalent to one pint of milk.
- Make sure you get adequate vitamin D through safe sunlight exposure during the summer months.
- A calcium and vitamin D supplement may be prescribed if calcium and vitamin D intake need to be boosted. Those over the age of 65 are at risk of having low levels of vitamin D so supplements are currently recommended (400iu Vitamin D).
- A drug treatment to make weak bones stronger and less likely to break may be prescribed by your doctor. There are a variety of treatments now available from daily, weekly or monthly tablets or injections and yearly infusions (drip). Bisphosphonates, such as alendronic acid, are a group of drug treatments commonly given to people with osteoporosis. Other treatments include denosumab, raloxifene, strontium ranelate and teriparatide.
- Pain relieving medications will help if fractures have already occurred.
- Exercise regimes which mix weight bearing exercises with adequate rest periods to prevent any flare ups of the arthritis. 'Weight-bearing exercise' means any exercise in which you are supporting your own body weight through your feet or legs (or hands and arms). Strength and balance exercises may also be important to help prevent any falls.
- If you are unsure whether you have been assessed for osteoporosis do discuss your risks of developing fragile bones with your GP or rheumatologist.

The National Osteoporosis Society is the only UK-wide charity dedicated to improving the diagnosis, prevention and treatment of osteoporosis and fragility fractures. For more information about osteoporosis and the charity's work please visit **www.nos.org.uk** or if you would like written information contact the National Osteoporosis Society on **01761 471771** and request the charity's publication 'All About Osteoporosis'.

- Tips for filling in the form

+ Preparing for the assessment

+ Your rights

+ The outcome

Living with RA

Help for People Claiming ESA or PIP

We all know the benefits system can very confusing and stressful. If you're currently thinking about applying for Employment and Support Allowance, ESA, or Personal Independence Payment, PIP, or if you're actually in the process of applying or waiting for an assessment, you may be struggling a bit.

If you are, a bit of extra help for you is now available on the web at **www.c-app.org.uk**.

There you will find:

- Essential guides to ESA and PIP, with basic information about the process and your rights, and tips about how to answer questions on the application forms and at the assessment. Plus there are more detailed guides if you want to know more.
- Two signed videos covering the same ground if you prefer to get your information that way.

Most importantly, the site has two 'self-assessment' tools, which allow you to try out some of the questions that you may be asked at a face to face assessment. They've been designed with people who have been through the test, so they are simple and easy to use. Your answers to those questions will give you an idea of what the result of your assessment might be. You'll also be able to save or print a list of your most important answers, the ones that will score you points, so that you don't forget to talk about those issues at the assessment.

The site's not a substitute for getting help with your application forms from a CAB or Advice Centre, and it's always best to get a family member, support worker or advocate to accompany you to a face to face assessment.

But you might find it a good place to start, and it can help you prepare better for your assessment and communicate better with the assessor once you're there. We think it gives you a better chance of getting the right result, and that it might just take a little bit of your worry and uncertainty away.

The website has been produced by seAp, an advocacy organisation working in the South of England, and funded by the Legal Education Foundation and Comic Relief.

You can also go straight to their websites for the individual benefits at **www.esa-assessment.support** and **www.pip-assessment.support**.

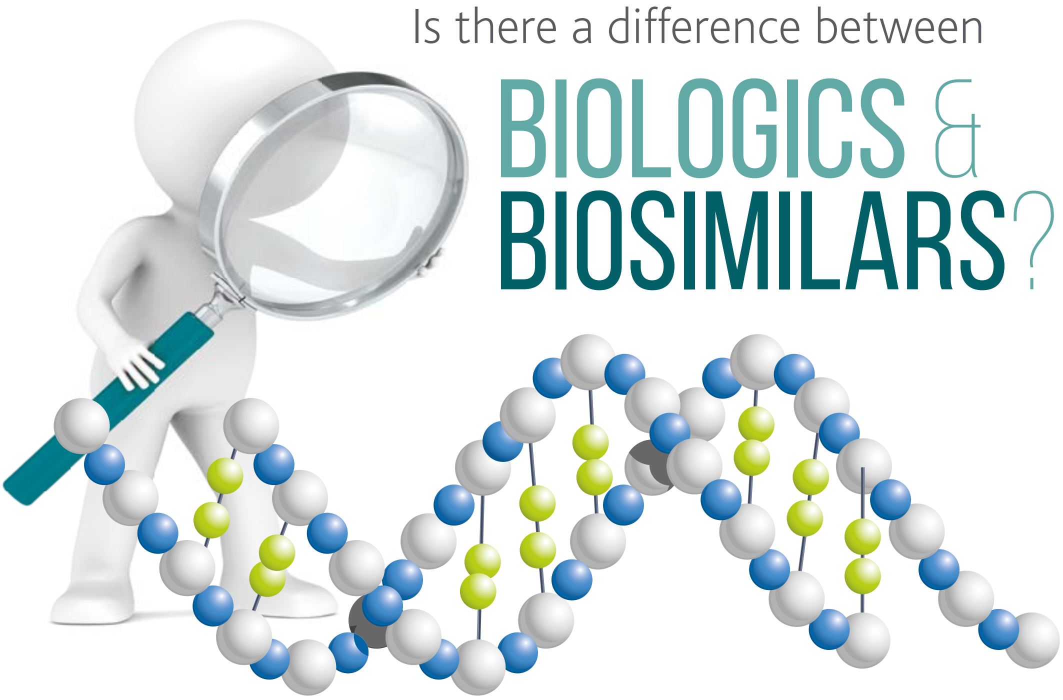
Living with RA

Biosimilars

What they are and what you need to know

By Ailsa Bosworth, MBE

CEO of NRAS



What are they and what do I need to know as a patient on biologics or as someone who may be going to start on a biologic at some point?

Many of you will recall an article we published on biosimilars in our Spring 2015 magazine. (You can find this article and more on our website about biosimilars www.nras.org.uk/biosimilars). In that article, we discussed two new biosimilar drugs, Remsima and Inflectra, which were introduced to the UK market in early 2015 as alternative options for infliximab (Remicade) Anti-TNF infusion. As relatively few people are on infliximab infusion therapy for RA by comparison to sub-cutaneously given biologic options, the arrival of Remsima and Inflectra didn't have a huge impact on the treatment of RA that was particularly visible to people with RA, although in the field of autoimmune gastro diseases (such as Crohn's and Colitis), where larger numbers of people use infliximab as the biologic of choice, there was more 'noise'. We are now a year down the line and a larger number of people with RA as well as Crohn's who were on infliximab have been switched to either Remsima or Inflectra without any significant difference being reported.

Since then, another new biosimilar for etanercept (Enbrel) has become available recently in the UK called Benepali which we believe will change the dynamics of the market in regard to RA as Etanercept is much more commonly used than infliximab. More biosimilars for etanercept will be coming to the UK market in the coming months.

Benepali has been granted marketing authorisation in the European Union (EU) for the treatment of adults with moderate to severe rheumatoid arthritis, psoriatic arthritis, non- radiographic spondyloarthritis and plaque psoriasis. Benepali is the first etanercept biosimilar referencing Enbrel to be approved in the EU, making it the first sub-cutaneous anti-TNF available here. Anti-TNFs are the largest component of the EU biologics market, accounting for some $10 billion of all biologics sold there.

If you are not familiar with the term 'biosimilar', how they compare to original biologics and how/why these are being introduced into the UK you can read more on the NRAS website **www.nras.org.uk/biosimilars**

Many more biosimilars will enter the UK market over the coming months

If you are currently on etanercept (Enbrel), you may find yourself in receipt of a letter advising that you are being switched to Benepali biosimilar.

Many more biosimilars will enter the UK market over the coming months and years as more original biologic drugs come off patent. So, it's important that all people with RA, but particularly those currently on an original biologic drug, understand what is happening in regard to switching and how they personally may be affected either now, soon or at some point in the future.

What is driving the switching?

Well, quite simply money. The biosimilars may be anything between 20-40% cheaper than originator products and this represents potentially large savings to Clinical Commissioning Groups/ Health Boards and NHS Trusts in regard to overall spend on biologics (bear in mind they are used in RA, Psoriatic Arthritis, Ankylosing Spondylitis, Inflammatory Bowel Disease etc.). With so many Trusts across the UK finding themselves in deficit and with increasing demand on NHS services, any ways to reduce costs are being grasped at as Finance Directors struggle to come in on budget.

What might this mean to me as an RA patient?

At some point, and particularly if you are currently on etanercept (Enbrel), you may find yourself in receipt of a letter from your Trust (or other form of communication) advising you that you are being switched to Benepali biosimilar. This happened recently to some of our members in the South West and they got in touch with us as they had concerns about what they were being told and were worried about what this might mean for them.

Are biosimilars as safe and effective as the original biologics they are replacing?

Generally this is the question which people want to have an answer to first, especially if they are doing well on their existing biologic treatment. When compared to their original biologics, all three biosimilars have demonstrated similar therapeutic efficacy and occurrence of drug-related events (side effects), they are well tolerated, and have a comparable record of safety. However, owing to the complexity of these drugs and their relative newness, NRAS still believe that ongoing safety monitoring is vital and long term safety data should be collected via the British Society for Rheumatology Biologics Registers in Manchester. We have said this all along and it is a recommendation in our revised 'position' paper.

Some of the specific questions raised by members who have been notified that they are being switched are:

- How long has Benepali been on the market?
- What is the safety and effectiveness record of this drug?
- Would this biosimilar be monitored by the BSR Biologics Register or a National Register set up for biosimilars or would it be left to the individual clinicians to collect data and thus could end up with no information sharing?
- This change is obviously a cost saving exercise for my Trust. However, if problems arise with the use of Benepali, would the funds be there for patients to revert onto Enbrel?
- Although biosimilars are approved by the European Medicines Agency- are they approved by NICE?
- What research findings are available to me as the patient on this drug?
- To ensure safety, will Benepali be prescribed by brand name only so there is no confusion for the patient?
- Who does the patient contact if they are unhappy with the said drug – in other words what is the complaints procedure if there is one in place?

We can help to clarify some of the information requested in the above questions. Our article has already addressed the first 3 bullet points. Clearly what happens if the patient experiences side effects following switching, which they hadn't experienced on the original drug, would be determined by the particular rheumatology team and their biologics pathway, and the first step for the patient would be to contact their rheumatology nurse specialist for advice.

NICE have made it clear that they will not be carrying out Single Technology Appraisals of individual biosimilars as they come onto the market following EMA approval. Their position can be seen here (www.nice.org.uk/news/article/evaluating-biosimilar-medicines). They have made it clear that a decision regarding the choice of biosimilar or originator biologic for an individual patient rests with the responsible clinician in consultation with the patient. The specific clinical trial data relating to clinical trials of a particular biosimilar can be found by entering an appropriate search request into Google or other search engines.

All stakeholders, including the Association of British Pharmaceutical Industry (ABPI) and the British Society for Rheumatology (BSR) have made it clear that all biosimilar medicines MUST be prescribed by their brand name to ensure that prescribing pharmacists, clinicians and patients alike can be assured that they are getting the correct drug. This is one of the recommendations in our 'position' paper too.

NRAS revise their 'Position Paper' on biosimilars

Since developing our original position paper back in the summer of 2014, we have revised some of our views in the light of the experience of the actual

introduction of biosimilars and the fact that the safety and effectiveness data being reported from across Europe and the rest of the world is pretty much the same as for the original biologic products. Furthermore, the designation of a biologic drug as a "biosimilar" by a regulatory authority demands that extremely rigorous quality controls are met with respect to characterisation of the biosimilar in relation to the originator drug. This can give us a great deal of confidence as patients. These quality controls for the biosimilars are much more stringent than were required for originators back in the early days of biologic DMARDs. We also have to adapt to the reality of what is actually going on in the NHS and the need to make savings where this is possible, feasible and the responsible thing to do, provided that quality and safety of care are prioritised and rheumatology benefits from some of the funds saved.

What specifically has NRAS revised?

In particular we have revised our recommendation "that no-one who is stable on an original biologic product should be switched purely on grounds of cost alone." We have changed our view on this because the safety and efficacy data is comparable to the original products and we would want to see the savings generated by using cheaper biosimilars reinvested to improve patient care and outcomes for people with RA and other forms of inflammatory arthritis. The NRAS revised position paper can be read on our website **www.nras.org.uk/biosimilars**

We have three very clear recommendations to make and we would like to work with other stakeholders to create a best practice 'national' switching policy which ensures that patients are properly advised and informed about switching in a way which prioritises proper care planning, shared decision making and does not leave patients anxious and with a string of questions like those listed. Unless we take such an approach there is a danger that these issues will be addressed differently in different trusts and parts of the country, leaving patients confused about what should be happening to them.

We think the following issues need to be addressed at a national level:

- Patients must be properly informed through robust shared decision making mechanisms about being switched – a template letter from the Trust sent to all patients simply telling an individual they are being switched, with inadequate information is not satisfactory or appropriate. The whole team needs to adopt a shared approach to this issue.
- The manufacturers must agree to long term safety data collection through the BSR Biologics Registers
- Gain share from the savings must benefit the rheumatology service and patient outcomes in an equitable way (i.e. any savings from switching patients should not all go to the Commissioners/Health Board or Hospital Trust for use in a completely different therapeutic area or simply to reduce deficits)

We hope that this article will go some way to help explain what is happening in relation to the adoption of biosimilar medicines for the treatment of RA in the UK as more of these drugs become available. It seems likely that some Trusts will be quicker to adopt switching than others and that there will be differences between the way in which these drugs start to be prescribed as mentioned above, which is why we would like to see best practice established quickly to prevent people being alarmed at suddenly being advised of a change in their medication which comes 'out of the blue'.

For more information, please visit our website: **www.nras.org.uk/biosimilars**

BSRBR
The British Society for Rheumatology Biologics Registers
Rheumatoid Arthritis

Biosimilars, the biologics register and you.

As patents begin to expire on some biologic therapies you may be taking for your rheumatoid arthritis, new drugs will come to the market based on the existing drug. Your local trust may elect to change your medication to the new biosimilar drug, all of which are fully approved by the European Medicines Agency.

The biologics register is extremely keen to recruit patients who are taking biosimilar medication. If you are receiving the Inflectra or Remsima biosimilars of infliximab or the Benepali biosimilar of etanercept you can contact your rheumatology specialist nurse and ask to be recruited to the biologics register. Alternatively, if you are already on the biologics register you can contact us directly by telephone on **0161 275 7390** or **0161 275 1652** or by email at **neil.wall@manchester.ac.uk**

Your contribution to the register is important in helping with treatment for rheumatoid arthritis and helping to ensure the long term effects and safety of biologic treatment.

BSRBR-RA

@BSRBR_RA

Fundraising

Climbing Mount Kilimanjaro

Emma and John celebrate the start of 2016 in style!

Emma said she was not prepared to entertain the idea that they wouldn't summit

On the 27th December Emma Thompson and her husband John did something a little different, they climbed Mount Kilimanjaro in memory of Emma's Uncle Dominic who lived with RA for many years and sadly passed away in July 2015.

Climbing is new to Emma, however her husband John is an experienced climber so his description of life on the mountain was very helpful for her. On New Year's Eve in the glamourous setting of an African mountain they played cards, had a nip of whisky and went to bed very early! They woke up to a lovely bright 1st January 2016, which would have been Dominic's 57th birthday, ready to continue their climb to the top of the mountain.

Emma found the climb both easier and harder than expected, easier because of a clever programme of acclimatisation, harder because nothing prepares you for high altitude. Not everyone makes it to the summit either and this climb was no exception, they saw climbers being taken back down the hill by guides. Emma said she was not prepared to entertain the idea that they wouldn't summit even though the effort it took to put one foot in front of the other was huge, so with John's encouragement they slowly made their way to the summit! They touched the summit sign, took lots of photographs and saw another climber propose to his girlfriend! What had been an eight hour climb up from summit camp became a three hour climb back down to it!

Emma said "I am so proud to have raised so much money for NRAS in memory of my unforgettable Uncle, I know that he would have loved telling people what we did"

If you are thinking of taking on the Kilimanjaro challenge Emma recommends the Lemosho Glades route, it has beautiful varied scenery and the gentlest possible acclimatisation but with enough hard work to make you proud of conquering something big!

Emma and John raised a "mountainous" £2,173.73 – simply fantastic, well done and thank you so much!

To read more of Emma and John's story or if this has inspired you to take on the challenge yourself visit **www.nras.org.uk/mount-kilimanjaro-trek-**

Book your place today or email **fundraising@nras.org.uk** for more information.

Fundraising

Why should I sign up to run for NRAS?

Michael Smith has decided to support NRAS later in the year – this is why.

It's been a couple of years now since that horrible moment when the specialist confirmed the news that my daughter Kelly had RA, a condition she will have to live with for the rest of her life. There was no consolation when he said that young babies are also diagnosed with the disease as Kelly was just 21 at the time.

Since that dreadful moment Kelly has grown to cope with her RA and has been having regular personal training sessions to enable her body to be as strong as possible, Liam from South Downs Health & Fitness has been fantastic. However when she asks me to make her a cup of tea because she can't lift the kettle to boil the water is when it really hurts me the most. I would swap our physical situation in a heartbeat as someone so young shouldn't suffer like this but they do! That's why I wear my NRAS wristband 24/7 to remind me of her condition, she can't turn it on and off so I support her by wearing the band.

We've talked about her getting a disabled parking disk for the days when walking is a problem with her joints, but then decide against it as the abuse she would receive from other car drivers who would see her as a beautiful normal girl just isn't worth it. They don't see the pain she suffers constantly, it's simply ongoing internal pain which has good and bad days.

Kelly wanted to prove herself so we have signed up to run the Royal Parks Half Marathon for NRAS. We have been training regularly together, it still hurts when she runs but she is committed to proving herself and raising money for NRAS."

Michael and Kelly are taking part in the Royal Parks Half Marathon on the 9th October. If Kelly's story has inspired you to join the NRAS team, or you would like to see what other guaranteed places we have in runs, please visit our website at www.nras.org.uk/runs and sign up today. If you would like more information email **fundraising@nras.org.uk** or call Val, our events fundraiser, on **01628 5015457**.

Thank you Kelly and Michael for taking on a great run for NRAS, you won't regret it!

> I would swap our physical situation in a heartbeat as someone so young shouldn't suffer like this but they do!

Press Release

BSR & NRAS respond to NICE decision

The following press release was issued jointly by the BSR and NRAS on 24th February 2016 in response to the negative outcome of our appeal to NICE to widen access of biologics/ biosimilars to people with moderate-severe RA with specific prognostic markers which would indicate poorer outcomes. Sadly our appeal was turned down in spite of the huge amount of work and overwhelming evidence presented by our organisations to the NICE Committee.

British Society for Rheumatology and National Rheumatoid Arthritis Society express disappointment over NICE appeal rejection on disability-preventing drugs that would improve patient care

The National Institute for Health & Care Excellence (NICE) have rejected a joint BSR and NRAS appeal against the Final Appraisal Document (FAD) on biologic DMARDS used in the treatment of Rheumatoid Arthritis (RA).

The current position allows the use of biologics drugs for patients with severe disease. While BSR/NRAS support the continuing availability of biologic drugs for patients with severe disease, we are extremely disappointed that NICE, despite the overwhelming evidence and convincing appeal case, refuse to extend the limited availability asked for to patients with moderate to severe RA. This group of patients can experience the same painful and debilitating symptoms of RA and, over time, just as poor outcomes as those with 'severe' disease. This position leaves the UK lagging behind Western Europe where there is greater access to these drugs.

We reiterate that we believe there is no economic or clinical justification for this to continue as the NICE Appraisal Consultation Document showed that the formula used to demonstrate cost-effectiveness for the NHS gave very similar results for both severe and moderate patient groups.

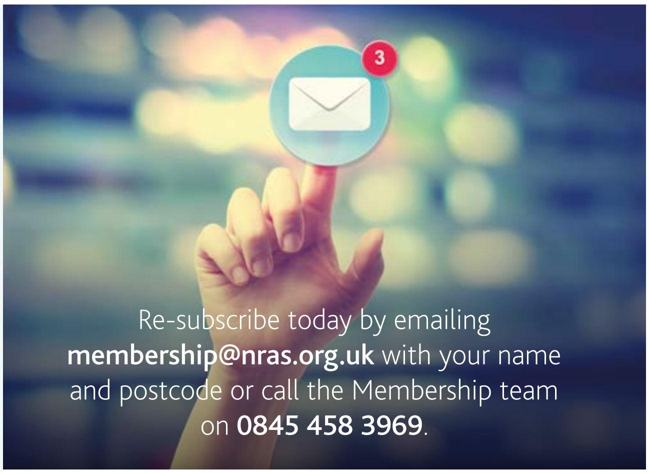
Professor Simon Bowman, President of BSR said "The clinical community remains frustrated that in this country we still fall behind other comparable European countries in the modern treatment of rheumatoid arthritis despite evidence to support prescribing of biologic drugs for those with so-called 'moderate disease'. These patients still develop joint damage and disability that in many cases can be prevented by biologic therapies. To exclude these patients from access to these drugs is a false economy that has wider impacts on the individuals, their employers, the entire NHS system and has a direct cost to the exchequer."

Ailsa Bosworth, Chief Executive of NRAS added "The impact on patients' lives of this negative outcome is significant. It is particularly disappointing given that we and the BSR were not asking for all patients in the moderate – severe group to be given access, but only those with the biomarkers which indicate poorer prognosis and outcomes. These patients will cost the NHS and society a lot more over time and it is short-sighted to refuse the most effective potential treatment to those most in need."

Help us keep in touch!

You may be missing out on important information

Lots of our Members are not currently receiving the NRAS monthly e-newsletters (quarterly for healthcare professionals). The e-newsletters are the easiest way to be the first to hear about the latest RA and NRAS news including events in your area, latest research and clinical trial information, new publications and much more! It's very easy to accidently unsubscribe, have emails get sent to a junk box or forget to give us your new contact details. If you haven't got an email address, why not ask if a friend or relative will receive the emails on your behalf.



Re-subscribe today by emailing **membership@nras.org.uk** with your name and postcode or call the Membership team on **0845 458 3969**.

Ask the helpline

Can I give blood?

I have RA and am currently taking DMARDs. I was wondering if I am able to donate blood?

Give blood

The information from the NHS Blood and Transplant service on this matter is as follows:

People may donate if they have not had any treatment to suppress their condition in the last 12 months.

People who are being treated with pain killers, anti-inflammatories, sulfasalazine or hydroxychloroquine as maintenance treatment for RA can donate provided that they have no associated cardiovascular disease.

Anyone on any other treatment to suppress their condition must not donate at all.

The same advice would apply to living bone donation or tissue donation after death.

With regard to organ donation, there are very few exclusions to end of life organ donation and rheumatoid arthritis would not prevent this type of organ donation. Living donation most often relates to kidney donation and very detailed individual assessments would be made in this setting.

You can find out more about your eligibility regarding being a donor by calling the Blood and Transplant service on: 0300 123 23 23 or visit **http://www.nhsbt.nhs.uk/**

External Affairs

15 Years – 15 Asks

Happy 15th Birthday, NRAS!

We'll be marking the actual day in October with no doubt more cake in the office, yummy but what could you do to mark this milestone in NRAS' history?

- Wear an NRAS wristband – great way of showing your support and raising awareness
- Host an NRAS Happy 15th Birthday tea party for friends, family and/or work colleagues.
- Nominate your Healthcare Professionals for a Healthcare Champion Award (see page 5)
- Recycle your ink cartridges, old jewellery or even your old car for NRAS!
- Volunteer to be an NRAS Phone Pal (page 35 to learn more)
- Ask about how to get involved in research next time you're in clinic.
- Tell your HealthCare professionals that they too can be Members of NRAS
- Nominate NRAS to a local business, school, golf club etc. to be their charity of the year
- Get your family and friends motivated to run, walk, cycle, swim or bake for NRAS
- Write to your MP (see **www.nras.org.uk/take-action**)
- Be a cheerer at an NRAS event (see page 39 for details)
- When you're finished with your NRAS Magazine pass it onto a friend or leave it at your GP or dental surgery or rheumatology waiting room.
- Get involved in your local patient participation opportunities to ensure Rheumatology service issues are raised
- Share your RA story to inspire, help others – email **media@nras.org.uk**
- Follow NRAS on Twitter and Facebook to spread the word.

NRAS will be celebrating its 15th birthday in 2016. Who knew from such humble beginnings – the front room of Ailsa's home – we'd be where we are today. NRAS, your society, is the leading patient voice for the 690,000 adults with RA in the UK.

nras
National Rheumatoid Arthritis Society

Research Update

Detecting Arthritis with Light

Early diagnosis means early medical intervention

Doppler ultrasound is more likely to detect arthritis at an earlier stage.

A finger scanner allows doctors to detect arthritis in its early stages. © Photo Fraunhofer IBMT/Bernd Müller

An early diagnosis and thus early medical intervention greatly improves the long term outcome of many diseases including many types of inflammatory conditions such as rheumatoid arthritis.

Experts at the Frauhofer Institute for Biomedical Engineering, Germany are working on an EC-funded project IACOBUS developing a finger scanner that will allow arthritis of the hand to be detected at a very early stage.

Human joints consist of layers of smooth cartilage and a synovial membrane which lines the joint capsule. The cartilage allows motion of the bones without friction and the synovial lining produces its own lubricant. However, severe inflammation of the synovial membrane in people who have arthritis disturbs this process which can in time result in damage to the cartilage and joints.

Rheumatoid arthritis has no cure as yet but when caught early and treated appropriately, the outcome for people with the disease is much improved. Conventional imaging techniques such as X-rays only detect typical features at an advanced stage.

Doppler ultrasound is more likely to detect arthritis at an earlier stage by showing changes in local blood flow. Increased blood flow in inflamed and thickened synovial membrane is a typical sign of the condition but detection at an early stage by ultrasound remains challenging. MRI scanning can detect changes earlier but is very expensive to be utilised as a diagnostic tool.

A European consortium, led by the Frauhofer Institute is developing an alternative diagnostic technique combining ultrasound technology with a 3D finger scanner that searches joints for signs of inflammation as well as other changes.

The scanner uses optoacoustic imaging techniques in which fingers are subjected to extremely short laser light pulses. As the tissue absorbs these brief light pulses, a tiny amount of warming is produced causing tissue expansion and pressure increases that can be measured. The process can be refined by scanning the finger with white light.

Dr Marc Fournelle, IACOBUS project manager says that "One of the advantages of this method is that it enables us to detect the condition while it is still in its early stages since many forms of arthritis affect the fingers first.

As always, the images produced by ultrasound depict soft tissue such as muscles, tendons and joint capsules which means our scanner gives doctors a familiar image to work with."

Research Update

Fresh insight into rheumatoid arthritis

offers hope for transforming patient care

Immune system protein has potential to prevent onset of aggressive form of rheumatoid arthritis.

A team of immunologists from Cardiff University have described how an immune system protein, interleukin-27, regulates the inflammatory process in an aggressive form of rheumatoid arthritis. They believe that what they have discovered has the potential to prevent the onset of this form of the disease.

The Cardiff team have been able to explain how this variant of the disease develops. They say that doctors will be able to divide patients into different sub-groups based on the varying patterns of the disease which is influenced by how much interleukin -27 is present in each patient's joints.

The course of therapy that a patient receives could then be decided depending on which sub group they fall into. Tailoring the treatment in such a way means that patients will have a much better outcome.

The identification of interleukin-27 involvement also means that there is the potential for new drugs to be developed to manipulate the inflammatory pathway controlled by this factor.

Dr Gareth Jones from Cardiff University School of Medicine's Institute of Infection and Immunity says "In all forms of RA it is widely understood that early intervention offers the best chance for clinical remission.

The key is in identifying which drug is best suited for each individual patient. Making the correct decisions early in the disease process will improve the disease outcome, enhance a patient's wellbeing and overall quality of life".

Professor Christopher Buckley, a researcher from the Rheumatology Research group at Birmingham University said, "The potential of interleukin-27 as a marker to stratify patients with RA into different groups is a very important discovery that will help transform our ability to use a more personalized approach in the management of patients with the most aggressive form of the disease.

Furthermore, identifying interleukin-27 as a bio-marker of the type of rheumatoid arthritis in which lymphoid tissue forms in the synovium, suggests that targeting this cytokine might be beneficial."

New Test to predict arthritis up to 16 years before it takes hold

Scientists at Oxford University have developed a blood test that can predict a person's chances of developing rheumatoid arthritis (RA) up to 16 years before it takes hold.

In RA, proteins are altered during inflammation in a process called citrullination. This causes an immune response that produces autoantibodies (antibodies that are directed against an individual's own proteins).

The researchers tested for antibodies that target citrullinated tenascin-C (cTNC), a protein which is found in high levels in the joints of people with the disease.

2000 patients were tested for the autoantibodies and in around 50% of the cases the disease could be diagnosed, including some cases not picked up by existing tests.

Professor Kim Midwood from the Kennedy Institute of Rheumatology at Oxford University said, " What is particularly exciting is that when we looked at samples taken from people before their arthritis began, we could see these antibodies to cTNC up to 16 years before the disease occurred – on average the antibodies could be found 7 years before the disease appeared. Early detection is key because early treatment is more effective"

www.telegraph.co.uk/news/health/news/12044901/Arthritis-predicted-16-years-before-disease-takes-hold-using-new-test

JIA & Me

Art for Arthritis!

JIA at NRAS
JUVENILE IDIOPATHIC ARTHRITIS

Physical illness, injury or hospitalisation often results in emotional trauma and behavioural problems for many children. Research has found art therapy can help children to express emotions more easily, develop positive relationships and can support how children communicate with their families and with the health professionals caring for them.

Research has found art therapy can help children.

JIA-at-NRAS is holding nationwide art competitions between 2015 and 2018 for children who have JIA as a means of providing an outlet for them to express what having childhood arthritis means to them and how it has and continues to affect their lives.

JIA&ME art competitions have been successfully held at the Nuffield Hospital in Oxford and Bristol Children's Hospital where children, young people and their families all came together for the day and celebrated. Already this year we've held JIA & Me art competitions at Southampton General Hospital on 30th January and the next one is on 14th May at the Evelina Children's Hospital in London; we have another in the planning stages for to be held at Sheffield Children's Hospital later in 2016.

The children and young people are asked to create a picture that describes what living with JIA means to them. The artwork can be a painting, a 3D creation, a photograph or a combination of words and drawing. There are three age categories 4-7 years, 8-11 years and 12-16 years; prizes are awarded for first and second place. At Oxford we were very lucky to have Joanna Brendon MBE from Chiswick to judge. Joanna who lives with rheumatoid arthritis herself is a renowned artist and you see some of her own work at her website **www.joannabrendon.com**. Unfortunately due to her own disease misbehaving Joanna was unable to judge JIA&ME competition in Southampton on January 30th but put us in touch with local artist Peter Jarvis who did a marvellous job at choosing the winners. Visit the website and facebook pages where you can see all the entries at **www.jia.org.uk/jia-me-art-competition**

Illustration through art shows an honesty and depth of emotions and expressions which the children and young people may not have previously expressed or made known in any way to members of their families or healthcare teams. This project will continue with children and young people who have participated being invited to be creative by entering the quarterly themed JIA &Me competitions starting in April 2016.

If you would like any more details on JIA & Me Art or you are a health professional working with children/young people with arthritis and would like to host a local event, please get in touch with Anne Gilbert, Youth and Family Services Manager **01628 823524** or email **anne@nras.org.uk**

My Story

A mother's tale

Sandy Winters shares her doubly delightful story with NRAS

By Sandy Winters

My consultant kept reassuring me that once I was pregnant there was a good chance my RA would calm down and I would feel a lot better...

I had been suffering extensive and extremely painful flare ups whilst trying to become pregnant. I found out at my 12 week scan that I was expecting twins and he said that probably explained why my previously ferocious RA had gone into remission so quickly.

My pregnancy went well and apart from feeling huge and uncomfortable towards the end I managed pretty well in terms of RA. But having two delightful baby girls came with a few extra issues I hadn't really considered:

The first one was physically lifting them up for feeding. Babies are actually quite heavy when you have to hang on to them all the time! I was breastfeeding to begin with and my wrists and arms were stiff and sore, and because of my actual physical size (I am quite petite with small hands) I had logistical problems getting them up to feeding height. I used every pillow in the house – or asked someone else to lift a baby up for me. I never did quite master the feat of double-feeding: where you feed both babies at the same time. One or the other would always stop and then I had no spare arm to move them. It was also fairly undignified if anyone came into the room!

I had been warned about the 'very likely' RA flare my body would experience after birth and I managed 8 weeks exactly before I gave in and started back on methotrexate. My GP had been able to give me steroid injections during the two months to tide me over as I really wanted to continue some level of breastfeeding for as long as possible.

For the first year we didn't have a dining table, it was re-designated as a large baby changing table. Two babies required double the space, double the mats, double the nappies... I had to do all the changes at table height as my knees would not bend and getting down onto the floor was (and still is) a bit of a drama and something easier not to have to do three times an hour.

Buggies – I needed something that a) was light and that I could push and b) would fit through our front door. So that immediately ruled out all the side-by-side buggies. In the end I had one with big air wheels that was light and easily turned. It was also the most expensive baby-related item we bought - but as it was also the only one we had, it turned out to be a good investment. I hardly ever folded it down as the catches were almost impossible for sore fingers. I also had big problems with carrying the baby car seats around as they were so heavy and unwieldy when my elbows and wrists were weak and painful. Fortunately at that time my feet and legs were not especially affected so I could manage to walk well pushing the girls in their buggy – I would find this much more difficult now.

I would lift the girls out of the buggy using the crook of my elbows to bear the weight when my hands were simply too sore. They very soon learned to help climb in and out themselves although they still remember fighting about whose turn it was to sit in the front!

My daughters understood early on that I couldn't always just lift and carry them as much as other parents could. 'Mummy's fragile' was heard quite often when out and about (especially in the ice and snow – fused wrists are not designed for catching your body weight if you slip and knees that don't bend are really not good for falls). However having two small toddlers balanced out nicely when we went off on walks as there was always one hanging off each hand!

By Zoe Ide

NRAS Trustee

National Audit

First year results of the National Audit of Early Inflammatory Arthritis/Rheumatoid Arthritis launched at the King's Fund on 22nd January

I volunteered through NRAS to be the patient representative on the Project Working Group for this British Society for Rheumatology led National Audit.

The Audit was commissioned by the Health Quality Improvement Partnership (HQIP) who are responsible for national work including the National Clinical Audit and Patient Outcomes Programme. It was so exciting after two and a half years hard work to finally share the first year's results and explain what the audit would mean for patients at its launch at the Kings Fund in London.

In summary the audit takes a detailed look at what happens, within those crucial first 3 months of referral to specialist care, to each new patient in England and Wales over the age of 16 with suspected Rheumatoid (RA) or another type of early inflammatory arthritis.

It measures speed of access to and quality of care including what clinical treatment is received, benchmarked against NICE Quality Standards in RA, how patients are helped by their rheumatology team to access information and services and what staffing levels/provision of specialist services are available at your local hospitals/trusts. It also gathers important information about the early impact of inflammatory arthritis on our lives, the affect (if any) on work patterns and how we feel about the care we receive.

The very first of its kind, this audit used data from 6,354 new patients collected from 143 trusts and health boards, representing 97% of NHS rheumatology providers in England and Wales

NRAS has been involved at every stage. Your society was instrumental in helping to identify a need for this audit, was involved in the development of the patient data forms and has enjoyed ongoing guidance from Ailsa (Bosworth) who serves on both the audit's Steering Committee and its Medical Advisory Board.

The reports mentioned below are downloadable and give the results in full. The patient guide is the easiest place to start as it summarises the clinician report and there are easy links to take you through to your local trusts. If you are newly diagnosed there is also information about what you should be able to expect in terms of care and some helpful explanations of terms and tools used by rheumatology healthcare professionals.

Both the patient report and the clinical report are available to download from **www.nras.org.uk/publications** as is a copy of the NICE Quality Standards of Care for RA.

> The very first of its kind, this audit used data from 6,354 new patients collected from 143 trusts and health boards

The annual report analyses data on 6,354 patients, who were recruited to the audit between 1 February 2014 and 31 January 2015. It enables rheumatology services to measure their performance against NICE Quality Standards for the early management of inflammatory arthritis and rheumatoid arthritis, benchmarked to regional and national comparators for the first time. The data should prove invaluable to trusts when assessing any requirement for service improvements and there are a number of examples where the data have already been used to deliver improvements to patient care.

Key findings of the first year's audit:

- Only **17%** of patients were referred within 3 working days of their GP appointment
- Only **38%** of patients were seen within 3 weeks of referral
- **53%** of patients started DMARDs within 6 weeks
- **91%** of patients agreed a treatment target with their health professional
- **59%** of patients were offered structured education and self-management within 1 month of diagnosis

Trusts are reporting the following:

- **96%** Trusts have telephone helplines for patients

- **46%** consider they provide timely access to patient education
- **54%** have dedicated early arthritis clinics
- **100%** of respondents say they offer annual reviews

Patient Reported Outcome Measures, Patient Reported Experience Measures and Work

Over 3 the three months:

- Disease Activity Scores (DAS) fall, showing improvement in disease activity overall.
- mean DAS at follow up is 3.5 (down from 5)
- 62% have meaningful reduction in DAS
- 24% achieve remission
- mean reduction in RA Impact of Disease questionnaire 2.4 (down from 5.6) a meaningful reduction is considered to be 3 (or 50%)
- 12% of patients who returned a confidential information form said they were not working or needing frequent time off because of arthritis
- 78% of patients who returned a confidential information form felt 'overall I have had good care for my arthritis' though 12% did not answer this question 1% disagreed and the rest neither agreed nor disagreed.

The audit has shown considerable variation at trust level and its findings are important for patients, providing real data where none existed before about local trust performance enabling informed choices about care to be made. This information also helps providers and commissioners as it shows where patient care is good and where improvements are needed. As you can see these first year's results have shown a need for improvement particularly around speed of access to care which has become a key message this year.

The audit has also highlighted overlooked areas which could have a huge impact on care if properly addressed with relatively small change such as proper signposting over work/occupational support, **better sign-posting to organisations who can help such as NRAS**, better provision of structured education about the disease itself and clearer guidance re GP referral letters and structured annual reviews.

It has been good to see that improvements are already being made on the back of these results with some departments already reconfiguring their services and hiring staff. The second year results are due before the end of the year where we hope to provide further analysis. There will be then be a short break while we anxiously wait for to hear that the audit is re commissioned by HQIP so we can continue to build on this important work.

96% of Trusts have telephone helplines for patients

46% consider they provide timely access to patient education

54% have dedicated early arthritis clinics

External Affairs

NRAS Groups' Update Spring 2016

Northern Ireland group launch

As promised in the last magazine, here is an update from the last group launch of 2015.

Kim and Gill from NRAS flew into Belfast on the 21st October and drove along the beautiful scenic route to the north-west. That evening the group was launched at Altnagelvin Area hospital, with the full support of the fantastic rheumatology team.

As you can see from the photograph, the event was very well attended and we were all delighted as this is the first ever NRAS group to launch in Northern Ireland.

Gill and Kim from NRAS were joined by Dr. Philip Gardiner, Dr. Wing Hoi Yau both Consultant Rheumatologists, Dawn Small, Rheumatology Research Nurse, Janice Carlisle, Rheumatology Ward Manager and Eithne Boyle, Principal Physiotherapist, Rheumatology. Dr. Gardiner gave the keynote speech of the evening about the present and future treatments of RA and then the team formed a Q&A panel, taking questions from the audience on a wide variety of topics.

Also in attendance was James Connolly from Ulster University, who is working on a project with a glove that wirelessly monitors hand stiffness and the range of movement in people with RA. He was seeking feedback on this and it generated a lot of interest on the night.

We would like to send a very special thank-you to Dawn Small who was instrumental in the planning and organisation of this event.

We would also like to thank the five people who have volunteered to coordinate the new group: Nigel, Paul, Sharon, Audrey and Joan. Meeting dates and details can be found at www.nras.org.uk/groups/region/northern-ireland. We wish the group every success for their first year.

First group launch of 2016!

Tuesday 1st March was launch night of the first new NRAS group for 2016 in Rugby, Warwickshire. The event had been many months in the planning, with Kim and Gill first meeting with Consultant Rheumatologist, Dr Shirish Dubey, back in June 2015; with the full support of University Hospitals Coventry and Warwickshire (UHCW) it was agreed to book in the launch for early 2016. The evening took place at Rugby College and almost 100 attendees and many of the rheumatology health professionals from UHCW came along.

We were thrilled to be joined by Dr. Kaushik Chaudhuri, Clinical Lead in Rheumatology at University Hospital Coventry who gave the keynote talk of the evening and gave a general overview of RA and the future of RA medication including the role biosimilars will play. The healthcare professioanls Q&A panel to took many questions during the evening.The panel included: Dr. K Chaudhuri, Dr Shirish Dubey, Dr Tanya Potter all Consultant Rheumatologists, Sister Cathy James ,Rheumatology Specialist Nurse, Sister Jeannie Woods ,Sister Daycase services, Gnaeri Hodkinson, Occupational Therapist and Ann Hutton, Rheumatology Pharmacist.

Save the date!

Saturday 18th June 2016 2pm – 5pm

NRAS will be hosting a FREE open event for anyone in the London area living with RA as well as friends and family, health care professionals. Everyone is more than welcome to attend.

Taking place from 2-5pm at Diorama Arts Studios, 201 Drummond Street, Regent's Place, London NW1 3FE (full details to be circulated in due course).

To register your interest in attending email **volunteers@nras.org.uk** or call **0845 458 3969** to speak to Kim or Gill.

Group coordinator Kate Kelly also shared her RA story which was a heartfelt insight into her life and experiences with a good amount of comedy moments thrown in which had the whole room laughing! She and fellow coordinators Fran Payne and Shona McKee will organise ongoing group meetings, with the first to be held at Cawston Community Hall on 6th April – full details can be found on our website here **www.nras.org.uk/groups/warwickshire-nras-group**

A huge thank you to Dr Shirish Dubey for all his hard work in helping to organise this event, to Dr Chaudhuri for being the keynote speaker despite being on call that evening (definitely beyond the call of duty!) and to all the healthcare professionals who took part in the Q&A panel and to those that supported the event and especially to group coordinators and volunteers Kate, Shona and Fran who have been the driving force behind the launch event and really ensured that the night was a huge success.

What else is new for 2016?

As always, 2016 will be busy for the External Affairs team and we currently have the following events already planned for this year.

- Salisbury group Information Evening on the 17th March at Sarum College
- South Cumbria group launch on the 18th May at Westmoreland General Hospital
- Croydon group launch on 6th July at Croydon University Hospital

There are many more in the pipeline, so keep an eye on the NRAS website for more details or call Kim or Gill on **01628 823 524.**

The best way to find out what's happening near you is to share your email address with us. Please send your contact details to **groups@nras.org.uk**

Warwickshire Coordinators with Kim (NRAS), Fran, Kate, Shona and Gill (NRAS)

A Huge Thank You to Dawn Doyle

Dawn and her husband Des have been instrumental in running the NRAS group in West Middlesex for just over 8 years. However pastures new are beckoning and they are to live near Chichester, a lovely part of the world.

Dawn leaves the group in very capable hands Rita, Lorna, Jane and John are the new group leaders and will make a formidable team. Dawn wanted us to pass on her sincere gratitude to everyone who has supported her in the running of the group and the wonderful flowers that were presented to her at the last meeting she attended.

NRAS would like to say a huge thank you to Dawn and Des for all their hard work over the years and especially acknowledge that due to their contact with Mr Neil Wingerath for securing an annual donation to NRAS of £2000 from the Mrs Maud Van Norden's Charitable Foundation. Such donations make it possible for groups and NRAS to offer the support and advocacy for people living with RA across the UK.

All from the West Middlesex group and from NRAS wish Dawn and Des every happiness in their new home.

Fundraising

Two iconic half marathons

and NRAS has guaranteed places!

We will support you every step of the way!

Great North Run registration fee £50, minimum pledge £300

The Great North Run is Europe's most famous half marathon taking place this year on the 11th September, starting in Newcastle upon Tyne and finishing by the sea in South Shields. If you, or someone you know, is a half marathon runner and hasn't taken part in this run now is the time to don an NRAS running vest and pound those pavements!

Royal Parks' Half Marathon registration fee £75, minimum pledge £300

This half marathon takes place in the south of England on the 9th October, starting and finishing in Hyde Park. The route takes in some stunning scenery and parks in our capital city. Now in its fifth year, this half marathon has made a real name for itself and is one not to be missed.

We have guaranteed places in both runs so if you are considering joining the NRAS team visit our website at **www.nras.org.uk/runs** or for more information email **fundraising@nras.org.uk** or call Val on **01628 501547**. We will support you every (aching) step of the way with training programmes, a running vest, tips on how to stay healthy whilst preparing for a half marathon and so much more. The NRAS events team will even give you a resounding cheer once you cross that finishing line!

Make 2016 the year to run for NRAS!

Fundraising

Your Mission...

...if you wish to accept it – awaits you at the Grosvenor Casino Reading

Mission Impossible

Join us for an evening of live music

We are very excited to tell you NRAS is hosting an evening at the Grosvenor Casino in Reading on 27th May. **Mission Impossible**, an 8 piece band, will be providing the entertainment with hits such as *"Nutbush City Limits"*, *"Valerie"* and *"Happy"*; all guaranteed dance floor fillers.

Mission Impossible with lead vocalist Bernadette Powell will be performing in the Show Bar at the Casino. Tickets for the event are just £20 and this includes your entry into the casino and a buffet supper. There will also be a fun casino with a prize for the person with the most chips at the end of the evening! Also we'll be hosting a raffle with star prizes, which include a money can't buy experience for two at the iconic BT Tower Dining Club, two return tickets on the Eurostar to Paris, Brussels or Lille (the winner chooses the destination) and a gorgeous Citizen watch worth over £400

Local hotel Millennium Madejski Hotel are offering excellent rates for anyone coming along to the event if you wish to stay over, quote code **MAD25**. The hotel can be contact by calling **0118 9253500** or email **reservations.reading@milleniumhotels.com**

To book your tickets for this event or for more information visit our website at **www.nras.org.uk/events**

The chips are down but the beat is up!

By Adrian Essex

My Story

How I take action

to enjoy life to the full

As long as I can remember I've been sporty.

At school I was usually in the team, running or football or whatever. As a young man I played rugby and all through my middle years (1973 - 2002) I cycled to and from work. In my fifties I took up running, some days in place of my bike ride to work. So the symptoms of rheumatoid arthritis in 2014 were very unwelcome.

I am also a very bad spectator, having only on rare occasions been to watch a Test Match or top class rugby, and never, I'm pleased to say, have I ever paid to get into Association Football. I've had a bash at many sports and my favourites would be rugby football, ski-ing and athletics. All those years cycling to work in the West End and City of London must have helped keep me fit, and luckily I managed to survive the traffic. So the thought that perhaps I was about to be crippled by failings in my joints was not a pleasing prospect.

The first big clue there was a problem came on a summer evening at a concert given by the Crouch End Festival Chorus in Southwark Cathedral on 17th June 2014. Both my hands swelled up and turned blue. I was scared witless. I thought next they'd go black and drop off. Looking back further though, there had been minor symptoms in May and June - discomfort in my hips and shoulders mainly, and perhaps the few months of dry eyes (Sjögren's syndrome?) whilst wearing contact lenses were related. So I set about getting the NHS to work on my behalf.

I'd had a fair bit of recent experience with the NHS, though not for myself, so I knew the drill. The NHS moves at its own, glacial, pace (though glaciers are reputedly speeding up). Don't try to rush it, and do follow its protocols. My GP duly referred me to a rheumatologist at the local hospital and blood tests and x-rays followed. Of course, my own investigations had me suffering from a terrifying range of diseases all of them entirely attributable to the internet, the famous Dr Google! I think lupus and gout were my particular favourites. But it was actually not very long before I got a definitive, accurate, not based on the internet, diagnosis of Rheumatoid Arthritis. I had all the markers and based on those alone the prognosis was for the trickier end of the scale.On 1st August I was given a shot of steroids in the bum and things started to improve. Well done the NHS.

Along with the steroids I was given advice and other drugs. To start with I was offered methotrexate but before I was able to start taking this the team at the hospital must have had a conflab, and offered hydroxychloroquine as perhaps a less scary alternative. This seems still to be working. Well done the NHS.

I keep a diary of incidents of joint pain. Fortunately these incidents are, so far, with treatment, mild and not too frequent. Phew. Well done the NHS.

The major advice I was given by the rheumatologist was to keep up a regime of exercise, which is perhaps slightly counter intuitive. On the one hand you might think that if you've got dodgy joints you should give them a rest, so as not to wear them out, but on reflection you realise that iffy joints allowed to atrophy will pretty damn soon stop being iffy and become completely useless. So I do still exercise. Yoga, decathlon and cross country, mainly. And I cook, from one of those companies that delivers a box of ingredients and three new recipes each week. So nutrition is taken care of. And I write odds and ends like this on a blog. So mental stimulation is taken care of. And I do like repeats of Dad's Army, and watching minor celebrities on television eating unpleasant animal's private parts to a commentary from vindictive Geordies, so laughing out loud is taken care of. And I've tried internet dating, so some other personal needs are taken care of too, thank you very much.

So that's probably it. My recipe for living life to the full is:

1. accurately (accuracy is very important) identify the problem
2. strike up a good relationship with a capable set of medical practitioners.
3. do what you're advised (mainly)
4. get lucky with the treatment
5. get on with it – carpe diem
6. laugh out loud every day – nil desperandum
7. write things with lots of latin tags in - quod abundat non obstat

Of course, such a recipe does not arise out of nothing. As well as the immediate rheumatoid arthritis problem there's the rest of my life which has influenced all this. The context and the inspirations that have led me to be where I am today. These include inspirational friends, the benefits of Yoga, my ambition for a touring holiday on my far too big motorcycle and especially my family. An amazing mother of 90 who I struggle to keep up with whizzing around Morrisons and my three daughters one of whom has just produced grandchild number 1 all who spoil me and look after me. Oh did I mention a lady friend, say no more, nudge, nudge, wink, wink!

> I keep a diary of incidents of joint pain. Fortunately these incidents are, so far, with treatment, mild and not too frequent.

External Affairs

NRAS North East 10th Anniversary

I was delighted and proud to be asked to present at our North East group's 10th anniversary meeting at the Freeman Hospital, Newcastle on 25th February. Our North East Group was the very first NRAS group to be established in the UK and so it was a very special evening hosted by Group co-ordinator and tireless NRAS supporter Eleanor Houliston.

Eleanor and Ailsa

By Ailsa Bosworth, MBE

CEO of NRAS

Group Co-ordinator Eleanor Houliston and Consultant Rheumatologist Lesley Kay

I was thrilled and surprised to be presented with a massive cheque for £1,000 at the start of the evening; "£100 for each year" said Eleanor, who travels around the North East with her committed colleagues in the group, raising awareness of RA and the Group and also raising funds for NRAS wherever possible. I was joined by Consultant Rheumatologist Lesley Kay, who also gave a presentation, updating the over 50 strong audience on The Freemans' achievements and growth over the past 10 years. The Freeman has attracted more health professionals to the rheumatology team providing greater levels of specialisation – particularly in disease areas like Lupus and Connective Tissue disease. In recent years they have also established a very successful early arthritis clinic which means that people with suspected early RA or inflammatory arthritis get fast tracked to diagnosis and get started on treatment as quickly as possible. Lesley spoke warmly of the importance of NRAS both nationally as an expert resource for patients but also of the key role the local group plays in the life of The Freeman.

Group Co-ordinator Eleanor Houliston said: "It doesn't feel like ten years since the NRAS team came to the Freeman Hospital in 2005 to hopefully seek patients who would be willing to establish a patient group. We are delighted here in Newcastle that this group has achieved ten years with so much support from NRAS and the Newcastle Hospital Trust.

It was wonderful that Ailsa came and gave an update of what the future plans were for NRAS and also looked back at their achievements since NRAS was formed. Everyone who attended the event was delighted that Ailsa had spoken with them all individually after the presentations. Dr. Lesley Kay spoke at the very first open meeting held in the Freeman Hospital and has been very supportive of the Group. Thanks to everyone who has given their time and support to the Group over the last ten years and we look forward, with their continued support, to the future".

NRAS wish our friends and colleagues in the North East continued success with the group and congratulations on 10 years of great service and support to people with RA living in the area.

External Affairs

Methotrexate Survey Summary results

By Clare Jacklin

Many of you will have completed a survey last year about the role healthcare professionals and your own research play, in influencing your treatment pathway and choices.

As always, there was a fantastic response with almost 645 respondents from all corners of the UK completing the online questionnaire and providing lots of valuable information. We have yet to fully complete the report on the findings but we thought it would be worth sharing with you some top line results in this issue of the NRAS Magazine.

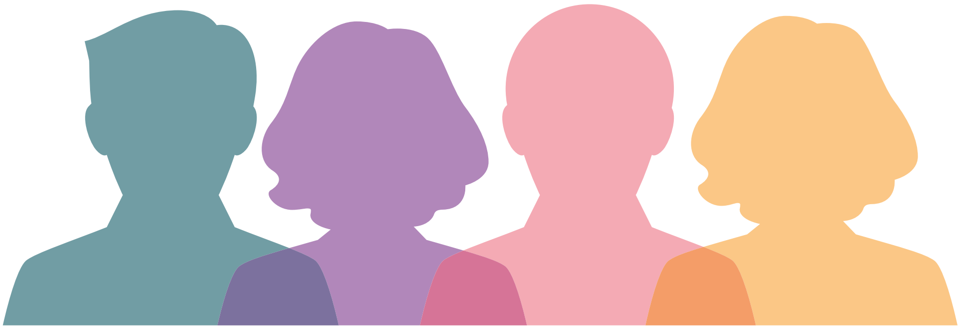
After first consultation with a rheumatologist

43% started treatment immediately after initial consultation

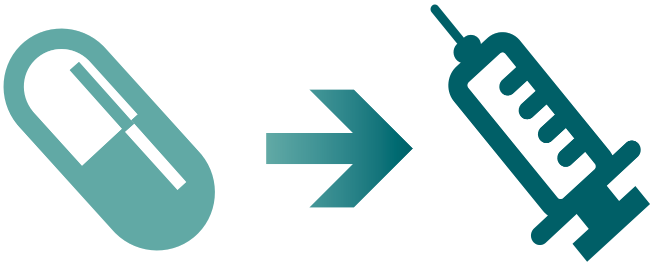
80% felt very confident about the treatment they had been prescribed

30% stated that the consultant did not discuss the benefits or side effects of treatment

2% of patients were started on injectable methotrexate following only 7% being given the choice between oral or sub cut methotrexate at the first consultation



Switching from oral to injectable methotrexate



67% remain on subcut methotrexate after being switched from oral methotrexate

36% who were stopped on oral methotrexate were not offered the option of switching to injectable methotrexate

28% who had been switched to injectable methotrexate would have chosen this method from the start if they'd known it was available

NRAS would like to thank Medac for supporting this survey.

This is only a snapshot of some of the findings of this survey and a full report will be available in due course. For more information about methotrexate and other treatments for RA visit **www.nras.org.uk/medication**

External Affairs

"Those who haven't got it just don't get it!"

Join our NRAS Telephone Support Volunteer (TSV) team!

Alison Kent

Telephone Support Volunteer

That's what one of our peer to peer Telephone Support Volunteers once said and it sums up very clearly why speaking to someone else who has been there got the t-shirt can really make a big difference to someone in need of understanding and support. Would you be interested in sharing your experience of living with RA to help others? As an NRAS Telephone Support Volunteer (TSV) you will receive full training and it is a way of turning your experience to good use from the comfort of your own home. One or two calls a month would be about the maximum you may be required to do.

Many TSVs find it incredibly rewarding and quite therapeutic too!

To find out more about being a Telephone Support Volunteer contact **volunteers@nras.org.uk** or call the office and ask to speak to Kim or Gill.

Are you feeling lucky?

Playing the NRAS Lottery is a fun and simple way to support people with rheumatoid arthritis and juvenile idiopathic arthritis in the UK.

For just £1 per week, you'll be allocated with a six-digit lottery number, which remain yours for as long as you wish to keep playing. If you match three, four, five or six numbers in the correct place from the lottery number drawn at random you could win up to £25,000! Plus, 50p in every £1 comes directly to NRAS!

In 2015 we had four lucky winners win £1,000 – who will be our first big winner of 2016...?

Read more about the NRAS Lottery on our website
www.nras.org.uk/lottery

Spotlight on RA

Take a look at just some of the things people did during RAAW 2015:


Lincoln NRAS Group at ASDA


RAmble


WARM Group Tea Party


Rika at Plymouth Hospital foyer

RA Awareness Week 2016 : 13th-19th June

NRAS is again hosting RA Awareness week this June


Walkers raise awareness and funds for RA Awareness Week in Worcester

This year's focus is on ' Shining the light on RA'. The campaign has two different elements, which we want to share far and wide:

1 For those unaware of RA and NRAS

Together we want to increase awareness of the early warning symptoms of RA as well as how NRAS can help and support people through the early days after diagnosis.

Many people do delay seeking help from their GP when they experience the early symptoms of RA as they don't initially recognise them often putting symptoms down to overdoing things etc. As with all long term conditions, seeking help, treatment and support as early as possible gives the best possible outcome.

RA week provides a platform for raising awareness so that 3 of the key symptoms of RA: Stiffness, Swelling and pain on squeezing the knuckle joints, can be better understood and enable people to seek help sooner.

2 For those living with RA

RA awareness week will showcase the support and resources that NRAS provides, enabling people to better self-manage their disease and so take back control of their lives. With your help we will highlight the invisible symptoms many people struggle with on a daily basis including fatigue, pain and stiffness.

NRAS helps at every stage in the RA journey, at times of crisis and in times of remission. NRAS can offer many other services and resources specifically to help you every step of the way with RA.

During the countdown to RA Awareness week, NRAS will be providing more content on the website explaining how you can become involved and help your society to "Shine the Light on RA". Use the hashtag #SpotlightOnRA to help spread the word.

We also need case studies for press and media work, up to and during the week. If you'd like to share your story with RA email **media@nras.org.uk**.

Being active in your community is the perfect way to build awareness. Follow the link below to see how you can be part of RA Awareness week.

www.nras.org.uk/ra-awareness-week

Policy and Public Affairs

Scotland Campaigns Update

The Scottish Ambassadors meet in Edinburgh

By Sheila Macleod

Chair of the Scottish Ambassadors

It has been a busy spell with a promising programme of activity falling into place. In November the Scottish Ambassadors – we are now six in number - met in Edinburgh, welcomed Ailsa and Conn, had a thoroughly inspiring talk from our Scottish Patron to NRAS, Professor Iain McInnes, Director of the Institute of Infection, Immunity and Inflammation of Glasgow University, and we worked through plans for the NRAS Scottish campaign in 2016.

We aim to make RA Awareness Week the focus for a re-launch of the 'S Factor' poster campaign and a real 'push' on raising the profile and recognition of the condition among the general public. We are keen also to engage with, and increase the number of NRAS Members in Scotland during 2016. The Ambassadors are also planning to host a 'gathering' event in Forth Valley College, Stirling on 4th October. This gathering will include excellent speakers from the Scottish rheumatological community, the chance to find out how to make the most of and participate fully in NRAS, plus space to meet up, share views and raise wide-ranging questions. We'll keep everyone informed of the plans as they develop and hope to meet as many of you as possible in Stirling in October. And the third strand of the Ambassadors' programme – all the best plans have three main parts – is to work with other stakeholders in Scotland to heighten focus on the treatment and care of established disease to bring that more in line with the approach to early RA which we have seen and welcomed, such significant progress. The aim is that this would follow on from the Scottish Metrics for Assessment of RA Treatment (SMART) successfully developed and launched in 2015.

Much of what we have planned to take forward has been informed by interesting and valuable conversations with healthcare professionals in the course of visits to rheumatology teams across Scotland by the Ambassadors; we are most grateful for the opportunity this gave us and look forward to further collaboration. We are keen to explore anything we can do to help the professionals help people living with RA!

With dissolution of the Scottish Parliament in March the Cross-Party Group on Arthritis and Musculoskeletal Conditions formally ceases to exist; the intention is, however, that it will be reconstituted after the election and very much live to fight another day! Over the four-years of its term, the Group has gone from strength to strength with a complement of committed members and a full programme of excellent business. We are deeply indebted to our convenor, Margaret McCulloch MSP, and to her predecessor who inspired and launched the Group, the late Helen Eadie MSP.

Prof Iain McInnes, NRAS Scottish Patron

You spared 20 minutes for care

Thank you to NRAS Members and others living with RA in both Scotland and Wales who have participated in recent region specific surveys, each with a different angle looking at care.

In Scotland we were investigating the social care and support people living with RA are experiencing. The findings from this survey are being finalised into a report with the support of Dr Kathryn Martin from the University of Aberdeen. The impact of co-morbidities, the area you live and family circumstances upon your experience of social care has been particularly revelatory. We will be launching this report in the Scottish Parliament shortly after the election and hope to influence the future direction of policy making in this area.

In Wales, where we know anecdotally that access to services is not as good as it should be, we were seeking to quantify this. With the support of Kian Raafat, a government statistician who volunteered for a short secondment to NRAS, we have put together a brief report which identifies the strengths and weaknesses in healthcare provision for people living with RA in Wales. The NRAS team of Welsh Ambassadors will be following in the footsteps of their Scottish counterparts by visiting all rheumatology units across Wales with this report as the central talking point.

If you are in either Wales or Scotland, please take the time to share these reports with your newly elected Assembly Members (AMs) and Members of the Scottish Parliament (MSPs). The patient voice deserves to be heard and we have set up an "e-action" on the campaigns area of the NRAS website to make this a 3 click process for you. **www.nras.org.uk/take-action**

Policy and Public Affairs

NRAS - Your voice in Westminister and beyond

NRAS speaks on your behalf to key decision makers across the NHS, government and beyond. Sometimes our message naturally overlaps with others and it makes sense to work collaboratively, we regularly embrace these opportunities to have one message with many messengers.

Working with other charities representing people with fluctuating or progressive conditions is a natural fit. Recently, we worked with the MS Society, Parkinson's UK and the MND Association on a joint briefing to social care leads in England on progressive conditions (this document can be found at www.nras.org.uk/publications). It makes sense to speak with one authoritative voice when we can as this helps impress the importance of our message onto busy decision makers.

One of the many formal coalitions that NRAS is a member of is the Disability Benefits Consortium (DBC), a coalition of more than 60 organisations representing people who use disability benefits and campaigning for a fairer benefits system.

NRAS and other DBC members had severe concerns about some aspects of the Welfare Reform & Work Bill, especially the £30 a week cut to the Employment & Support Allowance (ESA) for people in the Work Related Activity Group (WRAG). On Wednesday 13th January the DBC organised a 'mass lobby' in Parliament. Over 130 people with disabilities or long term conditions (including several with RA) travelled to the Houses of Parliament to meet with their MPs to talk about the impact the Bill would have on them and others in their position.

NRAS Member & Volunteer, Katy Pieris, spoke to her MP, Paul Scully. Fortunately Katy does not need to make use of disability benefits at present but like many others with a progressive condition like RA, she welcomes the safety net they provide. Katy and Paul had a productive conversation about the Bill and about RA in general.

Commenting afterwards, Paul said: "As I sat on the Committee that examined this Bill when it went through the House of Commons, it was really useful for me to hear first-hand accounts of welfare reform. I used the opportunity to reassure Katy and others that the focus of changes to welfare were directly aimed at protecting the vulnerable."

A huge thank you to Katy and other campaigners who joined us on the day but it didn't end there, a further 70 people made use of the e-action tool on the NRAS website to express their concerns in writing.

Engaging with MPs and making them aware of RA and JIA is an important part of our awareness raising work. We look forward to working with MPs from all parties throughout the year and plan to hold three separate events in Parliament, the first during RA Awareness Week in June, a JIA focussed event in the autumn and finally the Healthcare Champions awards in November as described earlier in the magazine.

Katy Pieris & Paul Scully

External Affairs

Volunteers in Action

Mid Somerset Rheumatoid Group have come up with a Smartie idea!

Members of the Mid Somerset Rheumatoid Group have been busy raising funds for NRAS by filling Smartie tubes with either 20p or £1 coins.

This was the idea of committee member Lorraine Cooke, retired Rheumatology Nurse, and members started collecting in May 2015 and have so far raised in excess of £250. Lorraine is shown front row, third from left, with some of the committee and group members who have contributed to the fundraising effort. This is a fantastic, innovative, but simple way to raise funds for NRAS! Thank you to all at the Mid Somerset group who contributed.

NRAS needs YOU

Recruiting Volunteers now to support fundraising events!

There are many ways to support NRAS and make a difference to the lives of all those affected by RA and JIA and not all of them require you to actually raise funds! We really need to recruit Volunteers to cheer and shout at fundraising events cheer points across the country. When people are running, cycling, swimming, trekking etc. for NRAS there is something marvellous and magical to have people along the route calling out their names and cheering them on. That all important **thank you** as they struggle over the finishing line makes them feel it has all been worthwhile. **Could you be that "thank you" person?**

Perhaps standing out in all kinds of weather doesn't appeal so what about being your society's representative to receive that oversized cheque from a golf club or school or local company. If public speaking doesn't phase you in the slightest, would you be up for talking to local businesses or community groups in your area to put NRAS forward as a potential recipient for their chosen charity of the year?

Signing up to be a volunteer today will help make NRAS, RA and JIA more visible.

Email **fundraising@nras.org.uk** with your details and how you'd like to support fundraising or call **0845 458 3969** and speak to Val, Bronwen or Nikki.

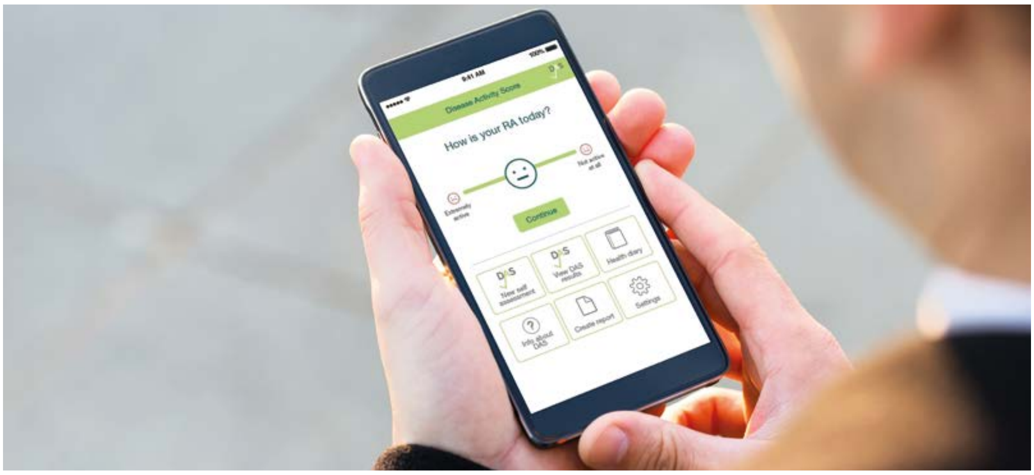
THANK YOU!

External Affairs

Know your DAS!

The 'Know your DAS' app is coming very soon

> The 'Know your DAS' app is designed to help you stay one step ahead of your rheumatoid arthritis.



We're excited to announce that the 'Know your DAS' app is here and will soon be available for you to download for free. The new app is set to be launched at the British Society of Rheumatology annual conference, the UK's biggest rheumatology conference for healthcare professionals, at the end of April (26-28 April)

The 'Know your DAS' app is designed to help you stay one step ahead of your rheumatoid arthritis (RA) and can be used to assess how well your treatment is working. We hope that having this tool at your fingertips will be beneficial in the management of your disease.

You can monitor and track aspects of your RA by calculating your Disease Activity Score, or DAS28 (so called because it assesses 28 joints in the body). DAS28 is a measure of how well your RA is being controlled – including how active your RA inflammation is. Some of the examinations involved in calculating a DAS28 score – such as joint examinations – can be carried out by you with advice and support from your healthcare professional. The DAS28 calculator is a key feature of the 'Know your DAS' app and, once your results have been input, you will be able to quickly and easily conduct the mathematical calculation needed to produce your DAS28 score.

Your progress can be shared with your healthcare professional and over time, these reports can be used to help build the best possible picture of your RA. What does this mean for you?

- Will help you take control of your RA and become proactive in its management
- Monitor and track aspects of your disease activity in between consultations
- Work with your HCP to make informed treatment decisions
- Speed up the assessment process during a consultation

Other important features of the app include:

- Health diary recorder
- Video guide to patient-assessed joint count
- 'Capture your own joint' camera feature
- Summary of results reporting tool

"NRAS has been working with Roche and Chugai to bring the 'Know your DAS' app to RA patients who might find it useful in the fight against their RA. The app is our first ever app and is a truly unique offering; we hope that its features will address the clear unmet needs that still exist in controlling the disease. Feedback from our patient user testing sessions has been resoundingly positive so we look forward to the app being widely available."

Clare Jacklin, Director of External Affairs

You will be able to download the 'Know your DAS' app for free on your mobile or tablet (available on Apple and Android), or from NRAS' website – **www.nras.org.uk** – so keep a watchful eye on your e-news bulletins to know when it's available.

The "Know Your DAS" app has been developed with the support and funding provided by Roche Products Limited and Chugai Pharma UK Ltd, to help people with RA more easily trace and manage their disease to enable better outcomes.

Editorial control rests with NRAS.

My Story

The Piddington Pod

When Christina Piddington was first diagnosed with debilitating rheumatoid arthritis (RA) 15 years ago, she left behind a life of grass huts perched on stilts in remote Western Samoa where she worked rehabilitating teenagers, and returned to the UK.

"I'd been experiencing extreme fatigue for a few years, and then in a lot of pain with swelling in all my joints," explained Christina. "I could hardly walk and was unable to drive. I was so ill that I was afraid it was something like bone cancer, so the diagnosis of rheumatoid arthritis was a relief in a way, but when I saw the prognosis and treatment, I was devastated."

But rather than getting back to reality with a resounding bump, Christina's experience as a therapist in alternative cultures had given her a taste for an unusual yet fulfilling existence, where she could channel adverse energy into something more positive.

And she's done exactly that. Despite also having dyspraxia and needing to rest regularly, Christina has spent six months building a sanctuary to live in, whilst also qualifying in Metalwork at UCA's Farnham campus.

Christina graduated from the University for the Creative Arts (UCA) this summer, where she built a 4.5 metre squared eco-pod as the final major project for her BA (Hons) Metalwork degree. On a brave and spontaneous impulse, Christina also landed herself a spot on the popular Channel 4 show George Clarke's Amazing Spaces.

"I'd been watching the show shortly after I'd drawn up plans for the pod, and the idea to contact them just came to me," Christina explained. "They've filmed whilst I've been working on the pod and getting my degree, so it's been a complete rollercoaster but a fantastic experience."

Growing up in an army family, Christina became used to a nomadic lifestyle and had a deep longing to create something that was hers. Feeling chained by rules and closed doors, Christina's strict upbringing and military past found her rarely feeling confident or good enough.

"I think my upbringing underpins a lot of my rheumatoid arthritis and dyspraxia – there was a lot of fear and anxiety, and it wore me out. Having my pod will mean I can be at one with nature again and will be a little bolt-hole away from everything for me to rest and recuperate."

Taking on a project of this size for a university project is unusual, and Christina's journey as a mature student with disabilities hasn't been without its challenges.

"I've had to structure my life around being in the studios and resting a lot of the time," she explained. "I've pushed myself too far at moments and got ill, because you get too carried away. It's because it's so wonderful to work on, but then everything hurts and you're exhausted."

Christina's route back to academia began in her mid-fifties when she studied an Access to Higher Education Diploma in Art & Design prior to her undergraduate degree.

"The mature student experience is more vocational, but in some ways I think we're all the same," Christina explained. "I've had help all the way too. Due to my arthritis I was entitled to support from a talented Student Learning Assistant, who is a UCA gallery technician and has helped all along with the build, and I've also had support to get my academic writing right and that's really helped me push my final grades up."

With over 200 tiles hand-cut from around 100 copper tanks, it's taken an estimated 600 hours to complete the pod. Now that the Piddington Pod is complete, Christina is keen to continue her creative studies and has recently started a Master's degree in Textiles at UCA.

"I'm studying part time so that I can work as a therapist alongside the MA," said Christina. "I'm looking at other ways to help others channel energy into creativity. When we're ill, we get depressed and feel powerless and hopeless. As a therapist, I've been working with turning that energy around and that will be the basis of my MA research.

Christina's therapeutic project has opened a new future for her in the crafts industry, and she has surprised herself. "It started off quite small at the design stage, but a university technician helped me see that I could build something bigger. It's definitely made me think that this could inspire other people – especially those with disabilities.

"You get fed up and think 'I'm a creaky achy middle-aged person with knobbly joints, always in pain', but I've turned it into something positive. My health is a lot better; I think the project has helped me. There's nothing like excitement to help you begin again!"

Christina's story featured in George Clarke's Amazing Spaces Series 5 Episode 7. You can find out more about PiddingtonPod at **christinapiddington.co.uk**

JIA at NRAS

JIA – an update


East of England Fun Day


East of England Fun Day


Bristol Art Competition winners

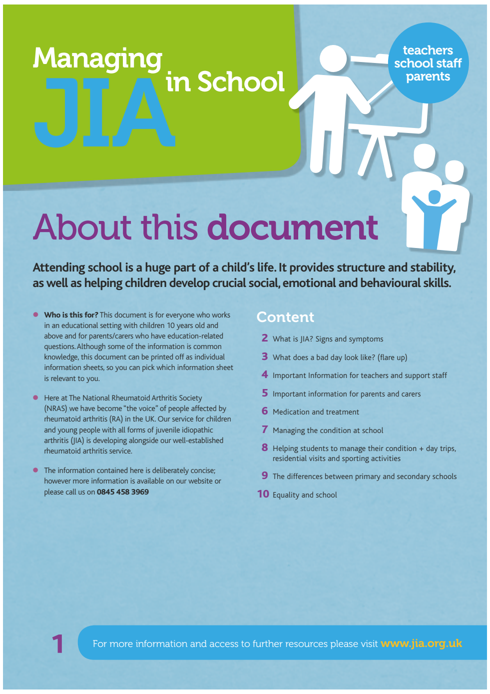

Charity wristbands

Since the last magazine a lot of the projects which were in the research and planning stages have now been finalised with dates and aims confirmed or published on the website.

We held an East of England family day at Newmarket racecourse on 27th February jointly with Dr. Kate Armon and the team from Norwich. These family days aim to help service users (i.e. children and teenagers with arthritis) and their families have their say in the future development of such services in the East of England where the health professionals are creating an informal managed clinical network across the region to improve care for paediatric rheumatology. On the 12th March we hosted a similar day in Cardiff for South Wales families. While the children are entertained with oodles of glitter, glue and sticky back plastic the parents and older children get to voice their concerns about services and listen to presentations from health care professionals offering those services. It is a truly collaborative project welcomed by both the parents, the children and the health professionals to ensure that future service developments have input from all stakeholders. Our goal is to get Cardiff Children's Hospital commissioned as a specialist paediatric rheumatology centre for South Wales which is properly resourced as such and this is supported by Dr. Jeremy Camilleri, consultant rheumatologist at Cardiff University Hospital who attended on the 12th together with his nurse specialist Jane, and physio Rhiannon.

This year we are holding our annual JIA Family Fun day in Ilkley, West Yorkshire on Saturday July 23rd 11am to 4pm. A full programme will follow shortly and will include presentations and Q & A sessions with health care professionals from the world of paediatric rheumatology, pharmacy, physiotherapy and more. The day as always is child focussed; there will be plenty of fun activities for the children and young people and a buffet lunch for everyone. To register to attend please email **anne@nras.org.uk** or online at **www.jia.org.uk/annual-family-days**.

JIA&ME Art competitions continue to be really successful and a confirmed date for the next one at the Evelina Children's Hospital in London is 14th May. Full details available at **www.jia.org.uk/jia-and-me-art-competition-eve**.



Managing JIA in School

About this document

Attending school is a huge part of a child's life. It provides structure and stability, as well as helping children develop crucial social, emotional and behavioural skills.

- **Who is this for?** This document is for everyone who works in an educational setting with children 10 years old and above and for parents/carers who have education-related questions. Although some of the information is common knowledge, this document can be printed off as individual information sheets, so you can pick which information sheet is relevant to you.
- Here at The National Rheumatoid Arthritis Society (NRAS) we have become "the voice" of people affected by rheumatoid arthritis (RA) in the UK. Our service for children and young people with all forms of juvenile idiopathic arthritis (JIA) is developing alongside our well-established rheumatoid arthritis service.
- The information contained here is deliberately concise; however more information is available on our website or please call us on **0845 458 3969**

Content

2 What is JIA? Signs and symptoms
3 What does a bad day look like? (flare up)
4 Important Information for teachers and support staff
5 Important information for parents and carers
6 Medication and treatment
7 Managing the condition at school
8 Helping students to manage their condition + day trips, residential visits and sporting activities
9 The differences between primary and secondary schools
10 Equality and school

1 For more information and access to further resources please visit www.jia.org.uk

"Managing JIA in school" has been produced to specifically help school staff understand juvenile arthritis as well as support parents with school related questions and challenges. It is available to download in PDF format from **www.jia.org.uk/education** – alternatively you can request hard copy be sent to you in the post. We will be sending the information on this document to primary schools across the UK but in the meantime if you would like a copy sent directly to your school, please get in touch with **anne@nras.org.uk** or call her on **01628 823524**. We have also published all the information on medications for children and young people with JIA on the website. Do check out the new information which has been illustrated with some of the wonderful pictures entered into the art competitions.

Charity wrist bling! JIA-at-NRAS festival style bands are now in stock and can be purchased from the NRAS website shop. They are sold in pairs for just £3 including postage (insert photo of wristband). Young people and children can choose which one to wear to express how their JIA is affecting them on any particular day. Good day/Bad day bands are a great way to raise awareness of childhood arthritis as well as being a cool accessory to impress your friends. Order yours online today at **www.nras.org.uk/shop**

JIA at NRAS

Helen's story

Helen was a very happy and contented baby, but when she was about 6 months old she stopped sleeping through the night and could become unsettled for no apparent reason on some days.

As she got older, she started to develop high temperatures some evenings and over night that would be gone in the morning. When she was one, she started walking but with a limp and would often crawl instead or want to be carried.

The GP referred her to the Orthopaedic Paediatric department at the Nuffield Orthopaedic Centre in Oxford, who, after numerous appointments, could find no reason for the limping and muscle loss on her left leg. They referred Helen for physiotherapy and further paediatric appointments at the John Radcliffe Hospital in Oxford in an attempt to keep ruling things out. After just over a year when Helen was 2 years 4 months, we were sent back to the Nuffield to the Paediatric Rheumatology department as Helen had had a physio appointment on a day when her joints were flared up, and the phsyio suggested Juvenile Ideopathic Arthritis as a possible reason for the limp and muscle loss.

Helens arthritis was confirmed in that first appointment as being in her left ankle and both knees. The following week we were back at the Nuffield for steroid injections into her joints and the fluid around the joints to be drained off as a day case procedure. The next morning when she got out of bed she walked straight away rather than crawling for an hour or two like she had always done. The next few months where a whirlwind of hospital appointments; physio, hydrotherapy, occupational therapy (fitting splints to stretch the joints) and another set of steroid injection.

After nine months the arthritis started to affect Helen's wrist too, so the decision was made to give her methotrexate each week. Since then we have continued with 3 monthly check ups at the hospital and regular blood tests with the GP. Unfortunately when Helen was 7 she developed *uveitis and though brought under control each time, she has gone on to have 3 more instances of it.

The most poignant moment for us was when Helen was 4 and said that her Barbie could now wear high heels, as her ankles did not feel crunchy, like cornflakes, any more. The weekly injections of methotrexate keeps the JIA at bay, but are not looked forward to in any way, and we take each appointment as it comes and most of the time Helen sails though them.

She is now at secondary school and looking forward to her 12th Birthday, and thankfully the treatment she receives means she enjoys most sports and can lead a normal pain free life.

*uveitis – eye disease which can associated with auto-immune diseases

> Helen (4) said that her Barbie could now wear high heels, as her ankles did not feel crunchy, like cornflakes, any more.

Travel tips and information

Travelling in London

Now we're enjoying the brighter days many of us start thinking about holidays and travelling around a bit more. Here are some helpful tips and information to hopefully make that easier for those with mobility issues.

On 31st March 2016, thousands of Older Persons, Disabled Persons and discretionary Freedom Passes will have expired.

London Councils, the body which administers the Freedom Pass scheme, will already have written to people to explain about the passes expiring. Mostly it will be to check you are still resident in the borough and are still eligible for the pass. For more information please contact the Freedom Pass Helpline by phone on **0300 330 1433** or email **info@ freedompass.org**. The contact centre is open Monday to Sunday 8am to 8pm.

Competition

Win a Nomad Travel Case!

Planes, Trains and Automobiles…
Top Tips for Trips Wanted

Do you find packing your RA meds for a trip a bit tricky? Want to win a super Medium Travel Case specially designed for taking your meds away worth £33? All you have to do to be in with a chance to win this top of the range Nomad Travel Case courtesy of The Cool Icebox Company is share your best travel tips with us for the next Autumn 2016 Magazine.

Found a nifty way of making yourself comfy in hotel beds? Found the ideal way to cope with heavy luggage? Got a gadget you go nowhere without? Tell us and others and you could be taking your meds away in style on your next trip.

Send your top travel tips to Clare at **clare@nras.org.uk** or by post to **NRAS, 4 The Switchback, Gardner Road, Maidenhead SL6 7RJ**.

Winner of the first Cool Icebox Large travel case worth £40 was Marcia Levitan for her top tip *"Always keep your medication in your hand luggage when flying together with your prescription"* Congratulations Marcia and happy travels.

www.coolicebox.com

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National Rheumatoid Arthritis Society
Ground Floor, 4 The Switchback
Gardner Road
Maidenhead, Berkshire
SL6 7RJ

Email: enquiries@nras.org.uk
Telephone: 0845 458 3969
01628 823524
Freephone Helpline: 0800 298 7650
Fax No: 0845 458 3971
www.nras.org.uk

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